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ABSTRACT

This report synthesizes the discussions which took place at an international conference on profound mental handicap held in Madrid, Spain (November, 1984). An overview of the issues involved in helping people with profound handicaps cites several positive trends, such as education for all, family support services, home visitations by direct care practitioners, parents' active participation in their child's development, deinstitutionalization, employment opportunities, and the individual program plan. A chapter entitled "What Happens at Present" focuses on the ways in which parents of profoundly mentally handicapped children acquire factual information, cope with community reactions in a world designed for "normal" people, and handle deinstitutionalization and the costs of raising a handicapped child. A subsequent chapter looks at successful developments in the areas of interdisciplinary approaches, improved counseling, assessment procedures, communication and social behavior, personnel training, and integrated regional planning. The moral, biological, philosophical, and aesthetic arguments for taking action are also presented. A final chapter called "Getting It Done" discusses resources available for dealing with government bureaucracies, public attitudes, the media, and financial needs. A list of Conference recommendations concludes the report. (JDD)

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Profound Mental Handicap

ED 287247

The Ultimate Challenge

A report on the proceedings of an international conference held at Madrid, November 1984

By Mike Miles

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EC 200 554

International League of Societies for Persons With Mental Handicap

Profound Mental Handicap

The Ultimate Challenge

A report on the proceedings of an international conference held at Madrid, November 1984

By Mike Miles

Gisela Kachel

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Preface

Mankind in the twentieth century has taken up many awesome challenges, ranging from space travel and plumbing the origins of the Universe to unknotting the secrets of life in the DNA double helix; from polar exploration to design of computers which perform more calculations in an hour than the entire human race has performed since its beginnings. The technological virtuosity employed would have been unbelievable to the savants of previous centuries; indeed, it is amazing even to its practitioners at the end of the present century.

One area of life still challenges mankind in a way that would be understood without difficulty in most times and places of human history; a challenge to which the response by 20th century man is little further advanced than that of his ancestors and has indeed at times regressed to barbaric depths. It is the *challenge of profound mental handicap*, in which the normal assumptions of human growth and developing individual autonomy do not hold good, even allowing for extra time and effort.

The exponential increase of knowledge and the pinnacles of technological achievement in this century have tended to *accentuate* the "differentness" of those whose intellectual capacity is weak or virtually absent. The modern "virtues" of growth, speed, efficiency, productivity, profitability and high-profile image marketing seem to leave little enough room for the ordinary person let alone the person with any sort of disability. In the laser-sharp communications age the profoundly handicapped person is an anomaly, seeming to defy and negate the popular image of "progress". Yet the existence of such persons, whose participation in creating the future appears to be marginal, poses profound questions about the very nature of "progress" and the sort of social systems towards which each nation is evolving.

Theoretically, the availability of advanced semi-autonomous electronic apparatus opens up many possibilities for persons with profound mental handicap. Will such apparatus be developed to enable profoundly handicapped persons, for example, to choose, cook and consume their own food without lifting more than one finger? Or will priority be given to the use of such apparatus for the precision bombing of "enemy" targets at 12,000 miles distance?

What understanding and response is to be given by the individual, the local community and society at large, to persons with profound mental handicap? What *can* be done? What *should* be done? What in practice *is* done, and with what attitude, philosophy and objectives? What trends are discernible? What can be recommended to countries at various stages of socio-economic development?

These questions were debated, some more and some less explicitly, at the ILSMH Conference on Profound Mental Handicap, held at Madrid in November 1984. Organised in collaboration with the Spanish Federation of Parents Associattions (FEAPS), the conference was attended by more than 300 people from 45 countries.

Speakers from U.K., Spain, France, and Sweden addressed the topic of profound

mental handicap with ample discussion by the participants, many of whom were parents of profoundly or severely mentally retarded children. The following major considerations emerged during the conference:

- **New Knowledge.** Experience and techniques have now accumulated demonstrating that far more progress can be made with profoundly mentally handicapped persons than used to be thought possible. The traditional attitude that nothing can be done to help the profoundly mentally handicapped has been shown to be mistaken.
- **Inter-disciplinary Assessment.** To effect the fullest assessment of the profoundly mentally handicapped person it is necessary to combine the skills of professionals in several disciplines. Where these resources are not available, it is still possible for one person to make an adequate working assessment, using inexpensive techniques, independent of sophisticated technology.
- **Individual Dignity.** The human worth and dignity of the individual, however disabled, was reaffirmed and the need was underlined for a positive transformation of public and private attitude.
- **Home or Institution.** Debate took place on questions of normalization and of the comparative merits of home-based or institution-based care and rehabilitation. Both in this debate and in discussion of methods of better education for the profoundly handicapped it became evident that no single approach could answer every need. Professionals and families should be flexible in considering a variety of approaches according to the individual circumstances.
- **Aid to Families.** A variety of schemes and methods were described assisting for families and mentally handicapped families to care for their profoundly mentally handicapped member and to preserve their own mental and emotional balance, according to the social resources and attitudes of different nations.
- **Information to Governments.** Governments cannot be expected to know what families need or how best to help profoundly mentally handicapped persons, unless they receive accurate information and practical suggestions from advocates representing the mentally handicapped. Parents' associations need to take a more business-like approach to planning, financial management and advising local and national Governments.

The present report was commissioned by the ILSMH to provide, in the words of its President Peter Mittler, "an account of what was said, but also some discussion of what seemed to be behind the papers as presented; a book written in a single style, based closely on the papers and discussions but integrating all of these into a coherent volume that is issue-orientated and relevant, addressed primarily to parent organisations and direct care-givers and those who may be in a position to influence better practice, but also intended to be widely read by others as well". It is preceded by an Overview of the field by Professor Mittler as conference chairman.

The verbal content of 14 hours of papers and discussions with 9 principal speakers and at least 40 other contributors in 4 main languages is not easily reduced to a coherent shape and form. Even less readily may the underlying philosophical issues be discussed on a global plane. The ILSMH is becoming more truly *international* and thereby speaking with and

persons from backgrounds fundamentally different from the dominant European/ North-American culture and society. Many member societies have not adequately articulated for themselves the philosophical bases and directions in which they are working, and are therefore poorly placed to enter into debate on these underlying issues. Practically all member societies are in fact working with a coalition of viewpoints, whether within a single broad religious framework or within a plurality of belief-systems.

A great deal of the discussion is equally relevant to severely handicapped persons; indeed it was clear that in many countries the finer distinctions between degrees of severity were not capable of being drawn. It was also apparent that according to the adequacy of environmental design, a person might be a good deal less *handicapped* in one country than in another, with the same level of *impairment.*

While writing, the problem of terminology came up: should one refer every time to the "profoundly mentally handicapped person"? Or to the "person with profound disabilities"? Would an abbreviation be considered demeaning and depersonalising? Should the person be "He" or "She"? I have resorted to introducing some representative "real people": Suzie, Ramdas, Maria, Okeke, Zhenya and Salim, so that while the discussion goes on over their heads they may at least be presented as subjects rather than objects. At the same time, in order not to become unrealistic in discussion, these people appear with the prefix "PMH". This device will not please everyone, but it may be a step in the right direction.

I have adopted the expedient of assembling the contents under broad and to some extent overlapping headings: 1) What happens at present? 2) What can be done? 3) What should be done? 4) Getting it *done.* Such emphasis on "doing" may seem still to be dominated by a Western "activism ethic", but it appears to me that the majority of those involved with profoundly mentally handicapped persons do not spend their time contemplating the philosophical questions arising in their work, but are rather concerned to improve their *praxis.*

Spring 1985 *Mike Miles, Peshawar*

Helping People With Profound Handicaps: An Overview*)

Profound handicap presents us all with a fundamental challenge. Whether we are parents, professionals, administrators and politicians, or merely fellow citizens, we need to ask ourselves how much more can be done to help people with profound handicaps, and how much more can be done to help them to take a more active part in their own lives?

People with profound handicaps are easily overlooked or even forgotten. In many Third World countries, they may not live very long, because of the absence of medical technology which will keep babies alive in Western countries. Even abler children with Down's syndrome are rarely found in many African and Asian countries. If they do survive, they are often hidden from view by their families or by society; very few of them are likely to receive help, to attend any form of school or to find any form of work or training in adulthood. Their families rarely receive any support or assistance in helping their relative to be accepted by the local community.

No country, no society and no facility can afford to be complacent about its successes in this field. Even comparatively developed countries which have made major advances in providing high quality services for many of their citizens with mental handicap have often neglected those with the most severe disabilities. Many thousands will spend the rest of their lives in large institutions, receiving basic minimum physical care only if they are fortunate, but rarely enjoying access, even within the institution, to ordinary everyday activities, to the choice of what they will wear, what food they will eat, who their friends and companions will be, or how they will spend their day. Only a minority will have access to a structured programme which aims to help them to take a step forward every day in their independence, whether in learning to look, to listen, to eat with less help, to dress, wash and to manage toilet needs. Above all, very few will enjoy more than a few minutes a day of ordinary contact with another human being who cares for them as an individual. There are rarely enough staff members to spend more than a few minutes with any one person.

A number of countries in Europe and North America are now on the verge of a major movement of deinstitutionalisation. This means that a serious attempt is being made to bring many thousands of people out of hospital and relocate them in appropriate services in the community. In America, the movement began at the end oft the 1960s; in Britain, it is just beginning.

But who are the people who come out of hospital? Is it the most able, those who really do not need the services of the institution, those who should never have gone to hospital in the first place, those who can most easily be fitted into community services because people of similar levels of ability and similar needs are already in such services? In Britain, we now have strong government commit-

*) *Paper presented by Peter Mittler*

ment to bringing people out of hospital, together with special administrative and financial resources to do so. But this is only for 15,000 out of the 45,000 adults still in hospitals – those who are the most able. Fortunately, a certain amount of decentralisation in decision-making is possible, so that in some regions the decision has been taken to try to include all hospital residents, no matter how profoundly or multiply handicapped they may be. The plan in our Manchester region is to close small hospitals within three or four years, and to close the three large hospitals, each with around 1,000 residents, within ten or twelve years.

How can this be done? Is it possible to meet the individual needs of people with profound handicaps outside hospital? What staff will be needed, and how will they be trained or retrained? Will the local community accept them? Above all, what kind of services do they need in the community? Where will they live? How will they spend their day? What will they do in their leisure time? What kind of programmes will be needed to help them to become more independent and to do more for themselves?

It would be dishonest to pretend that answers to all these questions were available. Neither the findings of research nor examples of practice from the field can provide any of us with firm foundations on which to build. On the contrary, the little information that we have should make us cautious not to exaggerate the progress that can be made or to raise false expectations. There must be limits to what can be achieved. But one important difference between the past and the present is that we now understand a little better that the limitations lie not only in the inability of the handicapped person to learn. They lie equally in our own difficulties in learning to teach them. They lie also in our own attitudes of doubt and uncertainty about whether people with profound handicaps can be helped, whether they can live in the local community with success and with dignity. We ourselves are also profoundly handicapped in another sense – we have inherited a pattern of services from earlier generations who believed that mentally handicapped people should be removed from their local community and be congregated together in distant institutions. Although we are now trying to reduce the number of people in these institutions, many people are still unconvinced that these efforts should include people with profound handicaps. There are worries, too, that too rapid and too radical programmes may result in an unfavourable reaction that may damage people with less severe handicaps.

Positive Trends

What, then, is the basis of our commitment to helping people who are profoundly handicapped?

First, we can be encouraged by the fact that many are already living in the community, and that some of them have been helped to become more independent. From these experiences, we can try to derive some lessons on what is possible and what is needed.

Education for All
Some countries have passed legislation to ensure that all children must attend school, no matter how profoundly handicapped they may be, and no matter whether they are living at home with their families or in hostels or institutions. In other words, no child can be declared to be so severely handicapped as to be ineducable or unsuitable for education in school. In Britain, for example, all children have attended schools since 1971. These are nearly always special schools, but administered by the same public bodies that are responsible for schools for all children. Many of the children with profound handicaps attend special classes within these special schools, which have a somewhat higher number of staff to children than classes for other children in the same school. There is now a serious interest in finding a wider variety of teaching methods to help such children, and to try to avoid depriving them of the company of abler children.

Supporting the Family
Some examples of modern methods of teaching children with profound handicaps will be given by other speakers during this conference. My concern at present is to emphasise that such programmes can effectively help to prevent admission to hospitals; in the United Kingdom, children with mental handicap are now hardly ever admitted to hospital for long term care. But this is not only because better education has been provided; full-time education is only one way of supporting the family in their own support for their child.

A range of family support services is being developed in many countries today for families with a child or relative with a disability. Sometimes this takes the form of financial assistance, to help with some of the greatly increased costs which have to be met. Another and more personal form of support comes from members of community-based teams, often known as Community Mental Handicap Teams. Such teams which have been developed over the past seven or eight years usually consist of two core members – perhaps a specialist social worker and a nurse initially trained in the field of mental handicap but now working with families and in community settings. These teams work with children and families with difficulties and needs that cannot easily be met by the existing services, for example, children with profound handicaps, those with severe problems of behaviour or communication, children at points of transition between services: those about to start school, those just leaving school and transferring to adult services; families who are experiencing particular difficulties as a result of illness, old age or incapacity of one of its members, families who need additional help in considering the alternatives that face them and their handicapped child. Sometimes, the team member tries to help the family to work

closely with staff of schools or adult centres, in order to develop a consistent programme of helping the handicapped person to acquire a new skill, or to use at home a skill that is being learned at school or in one of the adult services.

Another way of supporting the family is to provide a substitute home from time to time. Short term care can be provided by another family, not just at times of crisis or exhaustion, but as part of a plan to help the child to have the experience of living apart from his parents for short periods. Short term care need not be given only in large institutions.

Taking the Service to the Client

One important feature of the work of community teams is that they work with families in their own homes. In other words, they go to where the client is, rather than expecting them to come to a specialised clinic such as a hospital or assessment centre. It is remarkable that it has taken us so long to realise that you cannot hope to understand or help a family with a handicapped member except by seeing them in the setting in which they normally live, learn or work. Of course, some forms of assessment or investigation can only be carried out in a hospital or specialist centre, but, in general, the difficulties associated with handicap are best understood and addressed in the real environment of the family home, the school or the work setting. We therefore have to find the means of helping families and other direct care practitioners to get access to advice and assistance from professionals who have, until recently, only operated from specialist centres. The Community Mental Handicap Team represents one approach to this challenge – they work directly with families and other staff but they themselves will need support and guidance from other staff – for example, doctors, psychologists, speech therapists, physiotherapists, occupational therapists.

This raises the difficult question of team work and how professionals with different backgrounds, training, experience and attitudes can learn to work more effectively together. Nowhere is this more important than in working with people with profound handicaps. Dr. Hogg's paper will provide information on the many additional disabilities suffered by people with profound handicaps; these call for an integrated and coordinated approach by different professionals. But because, in most countries, the different disciplines are too busy and too preoccupied to work really effectively as a team, we need to develop other ways of enlisting their skills and expertise. One approach involves what we now call the transdisciplinary method: that is, all professional work through one colleague who acts as a single point of contact for the child or family. For example, a physiotherapist may carry out an initial assessment of a child with movement difficulties, but then trains another person either to carry out the necessary exercises, or to help the parent to learn to do so. Similar examples can be given for other therapists, including psychologists. Very few treatments are so specialised that only one profession is equipped to carry them out; many other skills can be shared among professionals, as long as they communicate and share problems.

Partnership With Parents

Support for families can include exploring ways in which the family themselves can play an active part in fostering their

child's development. Many families are now working in close partnership with professionals, helping to plan short term goals, and helping the child to reach those goals. Not all families are able and willing to take part in detailed programmes of working with their child at home; their wishes should be respected, since only they can judge how much they can do. Clearly, professionals who regularly visit the family at home will be in a better position to understand the needs of families than if they merely see them in the more impersonal setting of an assessment centre of hospital clinic.

But families with a child who is profoundly handicapped face many problems over and above those confronting any family with a child who has a disability. The sheer physical exhaustion of meeting so many day to day needs; seeing very little, if any, progress in a child who is nevertheless growing older and bigger and more difficult to manage; being confronted by the relative impotence of professionals in devising ways of helping their child; and of course worries for the future when they will no longer be able to provide a home for their child because of age, incapacity and finally death.

These issues will be discussed by parents in later papers in this conference. I want merely to indicate that new ideas are now beginning to be introduced which are intended to meet the needs of all mentally handicapped people, including those with profound and multiple disabilities. What, then, are these approaches?

Where to Live?

I have already referred to two major developments: first, *the provision of compulsory education and the improvements* that are taking place in the quality of the teaching in the schools; secondly, *the development of support services for parents, especially in their own homes.* In addition, a number of countries are now beginning to provide ordinary houses with as many staff as are needed by the residents of that house.

Some people express doubts about the ability of profoundly handicapped people to live in ordinary houses. But they forget that, in many countries, the majority of children who are profoundly handicapped, already live in an ordinary house with their parents. Why should they not live in another ordinary house, either with a substitute family, or with staff who understand their needs? The support of understanding and sympathetic adults is crucial; without it, even an ordinary house can easily become an "institution". Such staff do not necessarily need to be highly qualified people; but they do need to be helped to teach each resident to learn on a step by step basis to become more independent. The staff, too, will need support, for example by receiving help and guidance from visiting specialists, such as members of the Community Mental Handicap Team. Without such support, they too can become isolated and demoralised, just as parents do if they are left unsupported.

Different countries have different priorities for what constitutes a home for profoundly handicapped people. In North America, Britain and Scandinavia, the emphasis is increasingly on ordinary houses, with only three or four residents, together with the staff to share the house with them. But there are also many larger communities, with perhaps 20–25 residents. When these issues were discussed at the

League's Habitat conference in Brussels in 1981, it became clear that philosophy and practice varied greatly within Europe. But whatever the size of the house, it is important that people who are profoundly handicapped are not excluded or forgotten. One approach is to include one or two profoundly handicapped people in a larger group of somewhat abler residents; this provides them with a more stimulating and demanding environment but it is important that the other residents should agree to such an arrangement, since their choice must also be respected. A second alternative is to group two or three profoundly handicapped people together in one house, with the appropriate number of staff, and to aim to help each resident to become more independent so that the high levels of staffing and support which will be needed initially can eventually be slightly reduced.

What About Work?

I have not mentioned work and occupation, but this represents the most challenging task of all. Few people can accept that it is possible for any mentally handicapped people to find open employment at a time of world recession and record unemployment. But a number of projects exist to show that it can be done. In particular, the work of the late Marc Gold and also of Tom Bellamy and his colleagues in Oregon and the Pathway scheme in England pioneered by MENCAP are all examples of a revolutionary approach to work: instead of training, preparing and rehabilitating people for year after year, the aim now is to place an individual directly into work and train him or her to do the work in the real setting of the factory, the office or the work place. The essential ingredient of success is the support provided either by a staff member or more often by an ordinary fellow worker who merely befriends the handicapped worker and helps them to cope with the social demands of their new environment. Most of these direct employment schemes have so far been limited to relatively competent workers; Bellamy's work suggests that more severely disabled workers can also be helped to take advantage of them.

The Individual Programme Plan

Finally, I want to emphasise the importance of working with each person as a unique individual. We are just beginning to develop skills of devising *a programme which is suited to the unique needs* of each individual person. No two people with mental handicap have the same strengths or needs; no two have identical personalities. Like the rest of us, they are all individuals, and have the right to have their individuality respected and their individual needs met. This is the biggest challenge of all.

What Happens at Present?

This first section is reported primarily from the experience of articulate middle-class families living in Europe who have had profoundly mentally handicapped members during the past 20 or more years, and have taken action to improve their situation. It could have been entitled "What used to be done". However, the pace of change on the broad front is slow for mentally handicapped persons in general, and for the profoundly handicapped in particular. It is probable that what *has been* for the past 20 years continues to be largely the case *now*, and *will be* so for another decade unless very determined efforts are made to improve it. The experience ranges broadly from Spain through France and Wales to Sweden, and it is evident that there must be many families in each country whose experience would differ sharply from those described.

Comments from some economically weaker countries indicate an even greater gap in facilities, expectation and attitudes. Conference participants from the Third World almost inevitably derive from the well-to-do city-dwelling "modern" sector, whereas the bulk of Third World populations are rural, poor, non-literate and outside the international communications exchange and network. An effort has therefore been made to include some description of the situation of profoundly and severely disabled persons in the rural Third World, since otherwise their position is seriously under-represented.

Like other mothers I love my child and I think he is the most lovable person in the world. I think he is beautiful. I can enjoy watching him for hours. His skin is soft, like a new born baby's, completely undestroyed, although he has pimples and needs to be shaved like a man nowadays. He is kind, has never in his life done any harm to anyone. He has an intitution like few other people and he is wise. You can never fool him with nice words – he only trusts reality. In a world where he is so helpless and where there is, in a way, no place for him outside the family and where he rarely is respected as a human being, he has managed to survive for 19 years. I love to be together with Magnus. When he smiles at me I forget anything else in the world.

As Magnus is my first child and also severely handicapped, I had great difficulties to know how to care for him and help him in the best possible way. I had not even any experiences how to handle a normal child.

G. Anden

Before the Event

Before PMH Suzie is born, or the accident or illness occurs that results in profound mental handicap, most European and North American families themselves form part of that "general public" whose reactions they subsequently encounter in the form of fear, distaste or pity. The expectant mother may worry at times whether her baby will be "all right". All parents worry about their children being injured by accident or disease. Yet these fears are seldom entertained for long. Rarely do they impel the doubter to obtain medical textbooks so as to be informed of all the possible mishaps. Health professionals being cross-questioned about possible severe impairments to future babies are likely to make soothing noises and perhaps a mental query about the stability of the questioner.

Far from anticipating any irremediable impairment, a family's expectations tend to be formed and moulded by the mass media advertising industry promoting consumer goods with images of rosy-cheeked babies, healthy, bouncing kids, bronzed young adult bodies full of vitamins and vitality, high achievers, the great and the good somehow associated with a particular brand of soap or breakfast cereal. Whatever the brand, the hidden curriculum teaches that the strong shall inherit the earth, blessed are the rich, happy are those who have; and woe to the weak and feeble for even what they have is worthless and they shall be tucked away somewhere out of sight, with pity or derision. In actual fact the weak and feeble do tend to be tucked away out of sight in various types of public and private institution for the elderly and frail, the mentally weak or unstable; the prisons for those who lack self-control and who flout the authorised morality; or dying of loneliness and boredom in single-occupancy multiple tenements and delapidated housing.

The future parents are thus almost all very poorly prepared for the arrival of PMH Okeke and Maria. Such mass media material as they may have encountered concerning disability tends to emphasize either the latest miracle breakthrough of surgery of the amazing achievements of armless pianists, the angelic quality of nuns caring for the "hopeless cases", or the unsaintly conduct of underpaid and neglected nursing assistants bullying their charges in a "subnormality" hospital. Directors of the mass media, understandably, do not consider it part of their job to prepare families at large for the eventuality of having a severely or profoundly mentally handicapped member added to them. Even were they to consider doing so, it would be an extremely difficult and probably thankless task. Even a regular series of broadcasts on the subject would hardly counteract the billions of dollars poured into advertising, with its celebration of health, vigour and achievement.

In respect of mental preparation, many families in Third World countries are in a better position than those in "the West". The realities of frailty and disability are undisguised and near at hand, at least outside the "modern sector" of the capital city. A blind beggar sits at the crossroads, a lame beggar outside the bank; the funeral procession more often carries a child's than an adult's coffin; a lunatic roars harmlessly in the middle of the bazar, while grossly under-nourished and mentally inert children squat listlessly in the

shade. Natural calamity visits frequently in the shape of floods or drought, while disease, famine and the landlord's debt-collector are regular callers. Families tend to be large, and arguably there is a lower emotional investment in any individual child out of a dozen than there would be if there were only two children.
It seems probable that in the developing countries folk beliefs concerning pregnancy and teratogenic influences are more prevalent and have broader credibility, including astrological observations and the parents' state of mind from the moment of conception onwards. While modern scientific investigators are currently increasing their attention to the prenatal period, millions of Third World families have traditionally observed certain dietetic practices and have attempted to protect pregnant mothers from undue stress and strain. Some of these practices presumably originated from an intelligent connection between damage or stress in the pregnant mother and damage in the subsequent baby. Other practices seem to have no empirical basis.

Even where there is good reason for parents to anticipate some impairment in their children, social pressures may be such as to impel them to continue producing babies. In the North West Frontier of Pakistan, for example, it is unusual for a man *not* to marry his first cousin, and a high proportion of genetic defects are seen in the resulting children. At the same time, every couple is expected to try to produce several healthy sons. This combination of custom and pressure sometimes obliges couples, who may even be medically qualified and well aware of the probabilities, to continue having children even after they have had several with identical severe impairments and when there is every prospect of further babies being similarly damaged. The life prospects of these children are of course distinctly gloomy.

Parents with previous child-rearing experience seem to be at some advantage in early identification of their disabled baby's problems, and in their general capacity to handle the child. In many Third World countries it is customary for older children to look after younger ones, and thus gain valuable experience for the time when their own babies arrive. Western nationals, and possibly the mainland Chinese in view of their policy of reducing family size to one or two babies, are often comparatively uninformed of basic techniques of infant and child care. On the other hand, in families where there are already several children, the parents will inevitably make less preparation for a new arrival and will have less time to devote to the unexpected demands of PMH Salim and Ramdas.

Harry Lackner

Caroline was born in August 1965.

It is always a great joy to have a child. And we were happy and so were her brothers and sisters, and the whole family.

But, she was not growing normally, and as she was the 5th of our children, we knew what it was all about – then, after some weeks during which we fought to make her eat and live, we asked the doctor. The verdict was: "she is not like the others and she never will be."

All parents know that moment; all know how hard it is and all remember the immense loneliness when they are told: it is often a real trauma. Few parents have not resented the inadequate training of medical doctors for this task. The information given by doctors to parents is often incomplete and leaves them with their fears, bewildered and isolated, ignorant of the help and guidance they can get from organizations other than official ones.

J. C. Cousin

Learning the Facts

The majority of parents with handicapped children of whatever degree of disability report that they would have preferred to have heard the news of their child's disability, or to have had their suspicions confirmed, in some *other* manner than that which actually occurred. Partly this may reflect the fact that they would rather that they had never been obliged to hear the news at all: anyone having to bear such tidings starts at a disadvantage. Nevertheless it seems clear that a great deal of improvement could be effected in professional practice. The time when parents are told, or have their suspicions confirmed, of their child's disability, may be crucial to forming positive or negative attitudes.

Parents report that the *quantity, quality, timing* and *manner* of giving information leaves much to be desired. Many feel that they were dismissed with a label but no explanation; others were deluged with information and instruction which they could not at the time assimilate. Some felt that the person informing them was unsympathetic, brusque, impatient; or pitying; or too technical. Many parents have been unable to get the answers they wanted at the time they wanted them.

To some extent the latter is inevitable, in the case of the infant PMH Suzie and Salim. It may be evident that Suzie is impaired, and this must be communicated to the parents, yet the exact nature and degree of impairment very often cannot be determined without lengthy tests and observation. Even then, prognosis may depend to a large extent on the ability and willingness of parents to engage in rehabilitative action. It is understandable for them to demand from the pediatrician or nurse "What exactly is wrong with Salim, and just how much is it going to affect his life?" But it unlikely that such questions *can* be answered satisfactorily, even if the respondent happens to know the questioner quite well.

The informant in many economically weaker countries is in an even more difficult position, in that there may be minimal public rehabilitation facilities. The professional in Peshawar is from time to time confronted with PMH Salim brought by parents who cannot read and who are extremely poor, from a village 100 miles away in which there is no electricity, no piped water and no health clinic. Parents have to be told that there is no cure, there is no residential facility where they can leave the child, there is no surgery or injection, no drug or equipment to make any significant improvement, and no prospect of discovering one by shopping around. There remains the task of suggesting that tender, loving care is the appropriate course of management. Since the males of the household spend

their days scratching a living in their landlord's fields while the women walk many miles gathering water and firewood, the prospect of them engaging actively in rehabilitative therapy is slight. They may be advised to keep PMH Zhenya reasonably clean and as comfortable as possible, to talk to her often, to take her out in fine weather to listen to the birds singing. Very occasionally the parents brighten up at this advice and say "Well, that's exactly what we *have* been doing!" More often, they proceed to the next doctor, acupuncturist, quack or adviser, seeking one who will sell them a charm or nostrum, or who will pronounce definitely in favour either of improvement or an early death.

By whatever means the facts are conveyed, parents usually experience a gamut of unwelcome emotions and reactions. Shock, isolation and a feeling of unreality are common: all around, the rest of the world is busy about its activities as though nothing has happened, while the parents feel that their world has changed dramatically and irrevocably. Disbelief is an initial means of gaining time while discovering how to come to terms with the news. Self esteem may be severely shaken, with feelings of shame and guilt, depending on the cultural context. Parents often grieve and mourn for the expected "normal" child who did not appear. It is common for there to be feelings of rejection and inability to cope with or to love PMH Ramdas and Maria, expecially if their appearance is bizarre. Anger may be called forth, venting itself on entirely secondary objects.

Definitions

At this point it may be reasonable to consider some definitions of profound mental handicap, and the difficulties of arriving at a comprehensible and universal definition. Much of what has already been said, and a great deal of what remains, is applicable to persons with mental handicap ranging from profound through severe to moderate. A person with a given potential ability might be profoundly handicapped in a society where everything is designed for the norm and no rehabilitation facilities are available; whereas she might be only moderately disabled in another society where more thought has been given to design for, and integration of, disabled persons.

This is in line with the concepts being popularised by the World Health Organisation, in which an initial *impairment* leads to a *dis-ability*, which in a given environment causes a person to be *handicapped*. The differentiation of these three words is slightly arcane in English and even more obscure in many other languages, yet the concept remains valid even if not transparently expressed.

The borders between different categories of mental handicap are arbitrarily defined, or are left undefined, since so many variables enter in. There has been a reaction during the past 20 years away from "labelling", since labels have sometimes served to set artifical limits to expectations of achievement. Yet inevitably in practice every professional in the field develops a certain judgement and estimate of the probable degree of a person's handicap. In countries with minimal diagnostic and assessment facilities it may be sufficient to have no more than two categories of handicap, Mild and Severe, as an approximate indication of the level and duration of rehabilitative treatment and special education that may be required. Any more sophisticated classification should depend upon a standardised and systematised method of assessment and comparison, which in most parts of the world is not available.

One of the principal Conference papers outlined definitions from three angles: profound retardation and multiple handicap as assessed by psychological testing; as classified functionally; and as defined for purposes of service provision. Perhaps the easiest approach to grasp, transculturally, is that of comparing the abilities of PMH Zhenya and Ramdas with those of normal young children in the same cultural context. "Some of the more able profoundly retarded multiply handicapped persons may be achieving some of the skills of a non-handicapped three year old child. The majority however, will fall below an 18 month level, and many will pass only the most basic items of child development tests. In our own work we have encountered children who do

not scoreon any infant items typical of the first week of life" (Hogg and Sebba).

The latter paper then points out that one or more additional impairments are usually present in PMH Maria and Okeke, which greatly complicates the overall picture and the methods of approach to learning. It is customary for parents to be unaware or uncertain of additional impairments, especially "invisible" ones like hearing impairment. A good deal of professional indifference is still encountered when it comes to assessing PMH Salim's additional impairments, because the belief remains widespread that "nothing much can be done for them anyway". The multiply disabled child also faces at every stage the problem that service facilities are usually designed for children with a single disability. In addition to the customary experience of rejection and avoidance by the general public, families discover that even the professional services from which they might expect help and comfort turn them away with "We do not have the resources to cope with his hearing loss / lack of mobility / behavioural problems / severe epilepsy etc. on top of such a degree of mental retardation".

Coping With the Community

In the midst of their own shock, bewilderment, revision of plans, attempts to get information and to assimilate what is happening to them, parents have to find ways of telling their family, neighbours, work colleagues and coping with their reactions. Very few of those people will be expecting any other report than "Mother and baby are doing fine". On learning that there are problems, many people "do not want to get involved"; others will jump in with advice in which their good intentions are seriously impaired by ignorance and a failure to imagine what the parents themselves must be feeling.

Reactions within the family vary along the whole range from brutal rejection by grandparents, or by the father abandoning the mother and child, to a warm, loving and interested acceptance. In countries where a married woman's status depends upon her producing healthy sons, rejection by the husband is not uncommon. It may be reinforced in societies where marriages are arranged by the respective families between men in their late 20s and girls in early teenage. It may occur even in societies where marriage is viewed more as a partnership of mutually attracted equals. It remains the case for many young husbands that the arrival even of a healthy baby involves a serious and not altogether welcome curtailment of their freedom and an increase in their responsibilities as well as the temporary loss of the wife's earnings; if it unexpectedly threatens to involve a much great and apparently permanent change, through the arrival of a profoundly handicapped child, the reaction may be one of flight.

Producing a baby is a major emotional investment risk, since normally about 6 months of expectation and 3 months of sharply reduced domestic productivity are involved, for an outcome that is largely unknown. In many parts of the world the investment is considered wasted if a girl is produced, or an impaired boy. Furthermore, in many of the same countries the chances of a baby surviving unimpaired to adulthood are less than 70%. Since every family wants to have at least 3 healthy adult sons, to carry forward the family fortunes and provide for parents' old age, it is necessary to have at least 9 children, several of whom will be regarded tacitly as a waste of effort. Even the more enlightened parents who are delighted to have daughters will still proceed in the attempt to acquire sons, such is the pressure of the traditional system, extended family demands and the division of labour in society whereby all public business is conducted by men. In this sort of climate, where it is customary to consider some of one's children as rather an unwanted burden, the outlook for disabled children is poor and for PMH Ramdas and Zhenya extremely dim. Producing a baby is also one of the major

"public examinations" undergone by a man or woman. During childhood, school exams are a painful obligation. One of the attractions of adulthood is the escape from being publicly weighed, judged and reported on, a process attended by nasty jolts and occasional humiliations. Examinations in adult life are mostly confined to the privacy of a doctor's surgery or a test of competence to drive a vehicle (though writers, designers, artists and actors voluntarily expose their arts to public criticism for the sake of earning and reknown). The production of a baby is unavoidably a semi-public process. When the design appears to be defective, and perhaps grossly so, the humiliation may be powerfully experienced; especially so in the case of parents who have been accustomed to excelling in whatever they turn their hands to.

The Conference speakers reporting on their experience as parents of profoundly mentally handicapped children were mostly positive about the helpfulness and warmth of their relatives and neighbours – but as people now prominently involved in the mental handicap world they may be an unrepresentative sample. Had their families and communities *not* given them a measure of support and encouragement they might not have found the strength to develop interests beyond their own child.

There are parts of the world where the custom is to expose disabled, deformed or sickly babies to the natural elements; in other words, to kill them. To do so is against the law of practically every nation, but the local community takes the pragmatic view that the law-makers are far away in the capital city, and meanwhile there is no prospect of a viable or tolerable life for the baby. Resources are scanty even for the able-bodied who labour for their own shelter and food. So, rather than maintaining the defective baby for a few months or years during which its demands may endanger a family economy already finely balanced between survival and starvation, the life is snuffed out. At a rather more sophisticated level, but with similar underlying rationale, the lives of impaired fetuses, premature severely disabled babies, and babies of normal date but with gross impairment, may be aborted or allowed to expire in modern Western hospitals. The grounds here are not so much that material resources are lacking to sustain life, but rather the perception that the loving care, status and dignity believed to be necessary for a worthwhile life will not subsequently be made available by society at large.

With less premeditation, but the same end result, an unknown number of profoundly mentally handicapped children die from excessive medication, or overdose of opium or other locally grown narcotic substances. This may result from a situation where a family finds itself unable to tolerate the crying or other distress signals, and finds no means of relieving the distress or perhaps even of identifying the cause. The solution taken is to address the symptoms and to sedate the child. The strength of the sedative required increases steadily as the body habituates itself to the drug, with deleterious effect. Sometimes it is the distress *signal* that becomes intolerable, as in the overcrowded housing in Third World countries where dozens of people may lose their sleep from continuous night crying. In other cases it may be the unrelieved *distress* that is intolerable, when no means of relief seem to be available, and the solution is a heavy overdose of drugs.

Against the Grain

Virtually all disabled people and their families in industrialised nations, from the first day of disability, run up against the fact that everything is designed for the norm or the superior. This is a feature partly of mass-production and partly of the limits of designers' imagination. Until disabled people appear in public en masse, participating in everyday life and impinging visibly upon the designers and market developers, they will not be seen as an economically exploitable market for which design modifications should be made. (In the long run, economic arguments seem likely to carry more weight than humanitarian ones).

In many developing countries there is less design standardisation, because industrial mass-production has not made such great inroads into markets served by cottage industries. If one needs a pair of shoes one goes to a man who measures the feet and cuts the material accordingly. If one foot is twisted through 60° then the cobbler adapts his accustomed pattern. The following stages of thought are sometimes discernible: 1) I will need to use extra material and more time will be required. 2) Price will be higher than usual. 3) Well, it is interesting to make a shoe that is different from the previous hundred shoes. 4) It takes a skilled craftsman like myself to get this right. 5) It is a pleasure to see this funny-shaped kid walking with my special shoe. 6) I will charge nothing for the craftsmanship: in this case it is service to God. 7) I will charge something for the materials, out of respect for the child's father. He asked for shoes, not pity.

Parents of PMH Zhenya and Salim discover that for their child even the few facilities designed for disabled persons do not fit their needs; while the rest of the world smiles at the idea that public utilities might be designed with provision for persons who can neither climb steps nor walk nor sit nor communicate. The first major areas of ill-design in the public environment encountered by parents are in *accommodation, transport, health care and education.* Housing is designed for standard size people with ordinary abilities. Doors, passageways, do not easily accommodate a wheelchair or trolley. Toilets may be large enough for an adult, a child and a potty, but not for one adult to help another adult to the toilet, or to change an adult diaper. Public transport presents problems even to mothers with small children of normal ability, and insuperable problems to parents with the large, awkward body of teenage PMH Suzie.

Health care systems are designed for ordinary people who fall sick and after treatment get well again. They adapt poorly to disabled persons who fall sick: one should either be disabled, or sick, but to be both at once is regarded almost as

a provocation. Even less are health care and rehabilitation systems geared to cope with degenerative disabling conditions where in spite of all efforts there is a steady regression and loss of abilities, sometimes occurring in children as well as adults. For such a person additionally to fall ill on top of the overall erosion of function is to place demands on the health care system which have generally not been planned for. Parents may detect the unspoken message: "Be reasonable! We are doctors, nurses and therapists, and we do our best to relieve suffering and to heal people. You cannot expect us to do much for your specimen of a child who just gets worse, like an old car that has a different problem every time it is taken on the road."

Health and rehabilitation professionals not surprisingly draw a good deal of strength and motivation from their successes. Their training and experience conditions them to expect that normally something positive can be done, or they can refer a patient to a specialist who can do something. PMH Maria and Ramdas tend to defeat the system: although some positive actions can be taken, it is rare for there to be sufficient coordination and duration of such actions for a positive advance to be seen. Furthermore, the turnover of health and rehabilitation personnel may be such that few are aware of the progress that has been made: seeing adult PMH Suzie functioning at the level of a normal 18 month old, the specialist may be unaware (even after reading the records) that 5 years previously Suzie was functioning at the 9 month level and that a great deal of effort has gone into extending her abilities. From the *health* specialist's point of view there may seem little to choose between having adult Suzie functioning at the 9 month level or the 18 month level.

In no country does the education system cater effectively for PMH Zhenya or Ramdas. In most countries, special education is at a rudimentary stage, often a watered-down version of ordinary schooling and therefore geared towards examination results. In structurally more advanced countries the future of special education is tied up with the debate on integration or mainstreaming, proponents of which do not readily find a place for the profoundly handicapped – that is partly because the profoundly handicapped have hardly any place in *separate* special education. Indeed, PMH Salim challenges the whole philosophy of "normalisation" or "social role valorisation" with which integrative actions are so often linked. Educators may find it difficult to discover any valued social role that could possibly be carried out by PMH Salim, or any reason why a person so evidently abnormal should be geared towards "as normal as possible" a style of life.

The position of PMH Maria in many Third World countries is both worse and paradoxically better, in respect to the ill-design of everything. *Expectations* are different; and the fulfilment or disappointment of expectations has a great deal to do with the experienced joy or sorrow of life. In an economically advanced and well-organised country, people expect a very wide range of public services, and feel angry and frustrated if PMH Suzie cannot benefit from those services because doors are too narrow for her wheelchair, no elevator is available, regulations prevent the use of an ambulance for someone who is not an "emergency" case, etc. In many countries, public services are available only to

a small percentage of middle-class city-dwellers, so most people do not feel frustrated by the lack of them. They would *like* such facilities to be available, but they are not yet psychologically conditioned to believe that their life is worthless if it is not filled with opportunities and possessions.

Adult PMH Okeke, living in an economically advanced country, may sit in his wheelchair dressed neatly in ordinary clothes, waiting for someone either to manoeuvre him upstairs to the toilet or to change his soiled diaper and clean him up. Either operation may involve being lugged about more or less like a sack of potatoes, or hoisted with a strap and pulley or with an expensive hydraulic lifting device. Okeke may have learnt to indicate his needs, and may cooperate with the procedure, but there is usually a degree of dependence, discomfort and indignity which is experienced several times every day. Meanwhile PMH adult Maria in a village in a very poor country feels the need to relieve herself. She is wearing solely a loose-fitting long shirt, and customarily lies in the shade on the floor of her family's hut. She has learnt to roll and push herself through the open doorway, round the corner and to relieve herself behind a bush, just as everyone else does. Then she rolls inside again. The nearest water is 3 miles away, but every two days Maria's sister rubs a sweet-smelling tree bark up and down Maria's body, which makes her feel fresh and clean. In some respects Maria's life prospects are dim compared with Okeke's; yet in other respects she has greater independence and dignity because nobody has yet designed an inaccesible, hygenic, flush toilet system, there are no steps or door-handles in her residence, no raised bed, no wheelchair, no demand that she wear a full set of clothes and appear as "normal" as possible in public.

PMH Salim, who lives in a Third World big city, has the worst of both design worlds. There are "modern" roads, public sewerage system and pedestrian pavements, so that Salim can be taken out in his wheelchair. But because the sewerage system is clogged and inadequate, flooding is frequent. Pavements are therefore built at twice the ordinary height, but they are cracked and rutted, and the Public Works Dept. did not think of making ramps at junctions to enable wheelchairs to traverse. In the rural areas there are no special facilities whatever, so PMH Maria lives with her family for better or worse. But in the city there may be a residential "home", warehouse or dump for "incurables", "vegetables" and such-like creatures, where he is at the mercy of poorly paid strangers. It is unlikely that PMH Salim will find in that "home" the level of kindness and participation in family life that his country cousin experiences.

Family Situation

It may be presumed on grounds of general population geography that the majority of severely and profoundly handicapped children live in Third World households often comprising three generations living at close quarters, with 6 or more siblings and cousins present, and child care shared among several adult women and older children. Many of them will live in rural areas where agricultural work has a seasonal rhythm and the daily collection of food and water also varies with climatic changes. Some will live in urban areas, usually in grossly overcrowded slums and shanty towns. Rather few will live in well-to-do families, whose lifestyle and expectations may be not dissimilar to those of wealthy Europeans 50 years ago, with the more tedious aspects of child care undertaken by servants; or of modern Western professional class families with gadgetised living environments and an au pair girl.

The situation of the majority, therefore, must be very different to that of those born to Western nuclear families in which child-birth is expected to be a short interlude in the life of a mother customarily engaged in paid employment outside the home. As previously observed, the situation of PMH Salim and Maria in the Third World is both more and less advantageous. The physical circumstances of life are very constricted, and health hazards are high. With infant and child morbidity and mortality rates ranging from 5 to 30 times higher than those for similar populations in Northern Europe, it is very probable that PMH Zhenya and Ramdas are at even greater risk and will be preferentially represented in mortality figures. Attitudes towards disability are often rather negative, and may be heavily coloured by religious themes such as devil possession, punishment for parental sins or retribution for misdeeds in a previous incarnation.

Yet the physical and attitudinal circumstances do not make up the whole of life. PMH Okeke and Suzie are presumably oblivious to their economic circumstances, and to the attitude of the general public outside their home. The very fact that public attitudes usually are negative, plus the structure of life and the division of public and private labour between males and females in most Third World countries, will mean that Okeke and Suzie spend the greater part of their lives at home, possibly concealed by their families, but at all events rarely exposed to the world outside.

Within the Third World home there tend to be far more *people* than in the Western home. The labour that may be required to give food, to change clothes, to help to the toilet, to give loving care and attention, may be divided among several people. Ordinary functions may

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However effectively we develop our techniques and however well we advance the services in which they are delivered, we must also keep firmly in view the fact that the profoundly retarded multiply handicapped person is part of a family and that his or her well-being is dependent upon the physical and psychological health of members of that family.

Hogg and Sebba

be simpler, such as the toileting described in an earlier section, the type of clothes customarily worn, or eating arrangements where the custom may be to sit on the floor and take food to one's mouth with the fingers: a practice more easily learnt by PMH Maria than, for example, to sit on a chair and eat with a spoon from a plate on a table.

In very many countries it is customary for children to sleep all together, whether 3 or 4 on a bed or the whole family on a single mat. In fact the whole of life tends to be conducted "at close quarters" with other human beings. Whether this arises primarily from living in cramped conditions or whether from an innate human desire for proximity is a matter for speculation. In either case, it may work to the advantage of PMH Zhenya, whose most fundamental need seems to be for loving attention. Although general public attitudes may be negative, and may even to a large extent be shared by the members of Zhenya's family, it does not necessarily follow that within the home Zhenya will fail to receive loving care. In a large household, everyone tends to have more experience of caring for the younger or weaker. There is also more experience of caring for elderly people who may have rather high status and respect while needing help with basic personal functioning skills. Sometimes there are one or two members of a household who develop a particular talent for personal care, and therefore take a larger share of these duties: – out of a dozen or more adults and older children, there is much more likely to be one person who does this sort of thing well, regardless of the prevailing public attitudes, compared with the situation of the small or single-parent Western family where the major burden still tends to fall on one person, usually the mother, whether or not she has any aptitude or desire to perform the required tasks.

The Third World family, certainly in rural areas and still to a large extent in the cities, does not expect the Government or the local community to give any help with social welfare problems, whether of handicapped children or frail, elderly parents, mental disturbance, narcotic addiction or whatever. These problems are nobody else's business but the family's. One could not express one's weaknesses to strangers, becoming the object of pity and charity and bazar gossip, without a very serious loss of face. Within the family, debate on what to do about the problem may continue over years and may arouse strong passions, demands and accusations, but the family will still be inclined to present a united front to the outside world, either denying that there is any problem at all, or minimising it and asserting that the family is well able to cope.

This phenomenon, which is widespread in Asia and in some other parts of the Third World, is not entirely absent from

The simplest and a very tempting solution to Magnus' and my own problems would be to keep ourselves isolated from the rest of the world. We are now such a team that we would function very well in such a symbiotic life. It would be much easier if I myself cared for Magnus all the time and trained and stimulated him after my abilities. Thus we would not need to have helping strangers in our home and in our private life, we would not need to beg and ask for help from others. We would not need to explain, explain, explain . . . and yet be misunderstood most of the time. Then we would have peace and quiet together, and we would enjoy light moments of life. Many parents to profoundly handicapped children live like that. I prefer to work for a society where Magnus and I could have a good life together – but as two grown up people.

G. Anden

the economically advanced countries though it is more likely there to be regarded as an aberration. There are still many larger families, extended families and multi-generation households in Europe and North America, despite the statistical trends towards small nuclear family households. There are still many people living in Welfare States who do not regard public services as being for *their* use, whether for reasons of superior social class, or pride, or inferior self-image or religious beliefs or ilegal status within the country, or antipathy towards the type of service provided, whether through negative image or actual adverse experience.

Such people are unlikely to make their voice heard in an organisation of parents, or any other pressure group, yet they are responsible for a certain number of severely or profoundly mentally handicapped children. The fact that they do not raise their voice or participate in campaigning associations does not mean that all is well or that no advocacy is needed on behalf of their handicapped member. It may not however be immediately obvious what approach should be taken in the case of families who reject or fail to participate in the facilities offered.

One such family may say, in effect, "The child is a thorough mess but she is *our* child and we will do whatever we can do. Whatever may be the reasons for her being like she is, we will bear with it. We do not complain, nor do we seek help. The child has been given to us as a test of our character, and our dignity lies in accepting the test. It is nobody else's business. Far be it from us to have a doctor, a social worker, a teacher, a nurse and a lot of other middle-class busybodies poking their noses into our home and comparing notes about our behaviour. Besides, the family that runs after those public services is in a more humiliating position than a crippled beggar whining for alms: – its weaknesses are exposed, its privacy is violated, and at the end it is fobbed off with a few gadgets, a little money and some barely perceptible changes in the child which are taken to justify the whole intrusion. There is no dishonour in experiencing adversity, but to expose one's troubles to the pity of paid State employees is the ultimate degradation".

This contrasts rather sharply with the experience, philosophy and recommendations of the International League, which

We took the decision at that time to try and live our lives as normally as possible, taking one day at a time. This was the first basic decision which we as parents took arising from the boys' condition. We have stuck to this principle for the last decade, although obviously the condition of Alun and Geraint has affected our lives in a major way and as is usually the case, the mother gets hit the hardest of all by such circumstances. Both of us have been unable to do some of the things we would otherwise have done, but we have tried to stick to this principle and live as full and normal lives as is practically possible.

D. Wigley

tend to derive from countries in which a family may say: "Our child is profoundly handicapped but his rights are no less than those of any other citizen. We have contributed to a system of health and welfare provision, which is run by the State but is answerable to every individual contributor. The child has the right to the best of every available facility, help, therapy, equipment and service. If such is not immediately provided then we will act as advocates on behalf of the child and will fight for his rights. Each child belongs to the whole community so far as responsibility for growth and welfare is concerned, this responsibility being undertaken initially by us as parents. Since no individual family can possibly provide an adequate growth environment for a child with such special needs, and our own right to a normal life, health and happiness would be seriously compromised if we were to attempt to provide everything by ourselves, it is our right to demand the State's provision and our duty to complain if that provision is not adequate."

These two views owe part of their very considerable difference to a fundamentally opposed view of the child in his relationship to the family and the State; part to a different estimation of the value and availability of professional intervention; part to a different concept of duty, rights, honour and dignity; and part no doubt to other personal characteristics of the proponents. It may be true to say that the majority of families would fall somewhere in between these two positions, with a mixture of pride and reticence, advocacy and demands. One common factor, unquestionably, is the willingness of either extreme to do whatever it perceives as being in the best interests of the child. But the *best interests* will be conceived in fundamentally different terms in fundamentally different societies.

Further *common* factors are the acknowledged stress and strain upon the families, the daily uneconomic consumption of time, the physical fatigue, the uncertainty of the future, the dangers of over-protection and the difficulties of judging the ever-moving frontier of capability, particularly in the adolescent and young adult. Every relationship in the family *may* suffer because of the domination of family life by the needs of PMH Maria and Ramdas. There will however be a tendency to ascribe to Maria and Ramdas all family problems and frictions, even when the same are in fact commonly experienced in families with no handicapped member.

Home and Institution

Some resolution of family difficulties is commonly achieved by deposit of PMH Zhenya and Suzie in an institution run by the State or by a voluntary organisation, whether for a short respite or on a long-term basis. In some Western countries this possibility appears to be diminishing as programs of "de-institutionalisation" are implemented, though it remains to be seen whether the "community-based" alternatives in practice turn out to be any less "institutional" than the previous systems. In many Third World countries, against the advice of Western "experts", large residential institutions are being constructed on the grounds that "there should be a place" where handicapped persons can be deposited and looked after by those persons with a taste for such work.

Experience with institutions varies a good deal from country to country, and within countries. As already indicated, the demand by families for institutional places for PMH Okeke and Salim is higher than the supply. From Okeke's and Salim's point of view, life in an institution where food and a comfortable environment are plentiful and where staff perform their duties with a reasonable level of skill is likely to be more enjoyable than life in a household whose members are strained beyond their endurance and are under severe economic pressure. Numerous studies have shown that severely handicapped people tend to make more progress in a well run "community home" provision than in a traditional institution. Particular families are convinced that their handicapped member is better off in their household than in an institution; while other families are equally convinced of the opposite. Other families perceive that their *non-handicapped* members would have more opportunity to enjoy their "right" to health, happiness, education security, if PMH Suzie were removed from the household.

The present situation is that some profoundly handicapped persons find place away from their families in custodial or hospital-type institutions and some in short-stay centres and some in community homes which may be at considerable distance from their families' residence.

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They may have the status of "patients" (being treated), or "inmates" (being guarded) or "residents" (being assisted to live their own lives as independently as possible) or full community members. Often there is a mixture of the above situations. Their own feelings and wishes are usually not at all easy to ascertain, nor do they have the intellectual equipment to weigh up future probabilities and current alternatives. Families very often experience some feelings of guilt and dismay at handing over PMH Suzie to be cared for by strangers, while recognizing that their own capacity to care for her has reached its limit.

It is probable that the majority of families are faced either with no choice at all, since no centre or institution exists, or if existing will not take PMH Suzie; or are faced with an unpalatable choice between a distant institution in which they have little confidence or their own in-home efforts which have become an intolerable strain. In rather few places is there a viable third possibility, that of in-home efforts supplemented or relieved by input from trained and paid assistants, with a reasonable financial allowance from the State to cover additional expenses.

Unfortunately, the establishments – when they are not created by parent societies – are often hospital-type institutions in which medical care may be excellent but where education and stimulation leading to personal fulfilment are often neglected.

J. C. Cousin

Under great pain I have learned: In spite of my lack of knowledge I am more capable to care for Magnus than an institution. And the most important: I can support my child with love and safety. Love is something you can never "buy".

I decided to bring Magnus home although I risked to have to care for him by myself for the rest of my life. I knew that I by my bid of defiance towards the society would make us stand outside the society. We would be forced to live on an island of love in a very difficult world. Twelve years ago there was no place for people like Magnus in the normal Swedish well fare society – and rarely there is nowadays either.

G. Anden

Who Pays?

At present in most countries the family bears practically all the extra expenses of having PMH Okeke. In some places PMH Maria's pathetic appearance is exploited for begging, whereby the community participates in her upkeep. Maria may appear in person for this purpose, or may be represented by a photograph or drawing in a charitable appeal. In economically stronger countries the community votes welfare provisions which relieve the family of part or all of the economic burden of living with PMH Suzie, but these provisions are seldom adequate for more than custodial management.

In most countries the majority of the adult population has no *effective* voice in resource allocation, even where the trappings of a democratic system exist. National and local governments change hands between small groups of powerful people who, once in Government, bend their best efforts towards maintaining their power base. Social welfare provisions act as a mild palliative for the grosser inequalities, hardships and injustices suffered by the ordinary person, and are manipulated as a means of extending political clout. There is however very little influence to be gained by providing for a very small and (through concealment) practically invisible population of profoundly mentally handicapped persons.

Even where the State makes an allowance there are endless "invisible" costs to a family from the ill-design and inadaptation of the whole living environment. Yet to set a fair level of financial assistance is by no means easy since families vary so much in their expectations and consumption. To raise a non-handicapped child also costs a good deal of money. When such a child is exceptional in the sense of being an outstanding athlete or student, families may put themselves to a very heavy expenditure in order to allow the child to fulfil her potential, for which there are not many State handouts.

The difference comes in the family's own feelings about the value of their extra effort and expenditure. Most people will feel that they have got more satisfaction for their money when they see their child win a national competition, compared with merely seeing their PMH child playing in a safe and comfortable home environment: – two families may have put in roughly equivalent amounts of time, effort and money to achieve these two different results. In either case, the parents are to some extent spending money on themselves – their image of themselves as a family, as people who live at a certain level and achieve certain goals, have certain choices and freedoms.

One major difference is that many families with a PMH child feel that they have been *robbed* of time, money, freedom,

the normal child who failed to be born; and so somebody should *compensate* them for their loss. Again, the quantity of compensation is impossible to gauge fairly, because it depends upon the family's strength of expectations. To *sustain life* in PMH Suzie living in Brussels costs very little more than to *sustain life* in PMH Zhenya living in a tent on the Mongolian plains: – a little food, a little warmth, a little love. The difference, whereby Suzie's family actually spend several hundred times more than Zhenya's, comes from the family's own demands and expectations. Suzie herself demands little more than Zhenya.

In the majority of nations, gross inequality of living standards is so normal as to be locally invisible; in some, indeed, it is enshrined in the national religion. In a handful of Western countries there is some sort of public commitment to a minimum living standard for all citizens, in the sense that it is not considered tolerable to see people starving in the gutter or existing in grinding poverty. To this end, taxes are paid and public services are instituted, including welfare allowances for disabled persons. These services and allowances improve and increase slowly as the public perception of a "minimum acceptable living standard" changes. Not surprisingly, this minimum standard is far below the expectations of the majority of the population for what they personally would find acceptable. Other people's discomfort tends to be a great deal more tolerable than one's own discomfort.

Positive Features of the Present Situation

It would be a mistake to present the current position in an entirely negative manner. The arrival of PMH Ramdas or PMH Zhenya in a family can bring certain benefits, whether comparative or absolute, in spite of the general inadequacy of services, discriminatory attitudes and inadaptation of society at large.

The "absolute" benefits tend to be those shared with families who have a severely or moderately handicapped child, and have affinities with those which may be experienced by people going through any major adversity. Many people rise to the challenge of difficulties. Some people gain an increased depth of understanding of themselves, more reality in their perceptions of life and of their own strengths and weaknesses. There is an adaptation towards living each day for itself, one day at a time; an appreciation of smaller joys and blessings; an awareness of the innocence and harmlessness of PMH Okeke in a world that is too often violent and deceitful. Although the existence of pain and suffering is taken by some people to be an obstacle to religious belief, many families report that their faith and belief has been strengthened by the experience of having a profoundly handicapped member.

The "comparative" benefits of having PMH Salim in the family, as compared with having less severely disabled Jose or Lee Hwan, derive mostly from the fact that PMH is obvious and extreme. There is no doubt about the difficulties, and parents are unlikely to be told by members of the public that "She will grow out of it", or "Can't you keep that boy under control!" If the difficulties grow too great for the family there is likely to be less blame or guilt if the child is "put away" in an institution, if the child is allowed to vegetate in a corner, or if the child dies during childhood.

There is in some cases the *hope* that the child will expire in a comparatively short time, even in families where no one would consider actively causing the death. There may be an anticipation that it would not be a bad thing if the life ran out in a shorter rather than a longer time. In practical terms the immobility of PMH Suzie may be easier to cope with in the home than the supervision of mobile severely retarded Jose who pokes his fingers into everything and climbs up and down the curtains.

The fact of being part of a small and rather rare group, i.e. having a profoundly handicapped child, may lend a significance and identity to a family that has not distinguished itself in any other respect; may indeed become a convenient excuse for failure to achieve any distinction. This may seem rather a weak "benefit", yet the reality of it is undeniable at least in the West, where the struggle for individual distinction and the appetite for individual

To conclude, I remind you that I am speaking as a parent. I will quote the text written by a friend of mine: "the person with a mental handicap, when he does not pass unnoticed, generally attracts sympathy because, beyond his intellectual limitations, he shows a freshness of feeling, screened from the usual deceits generated by the intellect. If such richness is not perceptible at once, it is because he is multihandicapped. To decipher and understand their wishes is to help to make them free. This is the reason of our action.

J. C. Cousin

achievement and attention is perhaps rather greater (or more openly recognised) than in other parts of the world.

Among the specific benefits in the present situation it must be recorded that a certain number of families, or individual members of families or institution staff, take delight in knowing and living with PMH Maria and Zhenya. The personality and human-ness of PMH Okeke and Salim somehow transcend their disabilities, to the point where they are no longer perceived as profoundly handicapped persons. What they can or cannot *do* becomes less important than *who they are*. Sometimes PMH Suzie comes across as very open, loving, full of fun, with a refreshing absence of the masks and reserve of "normal" adult intercourse. In that case, Suzie is clearly perceived to be making an input of goodness to the human race. As one special teacher put it, "The purpose of severely retarded people is to be joyful. That is what they are there for, to bring joy, to give joy."

Elisabeth Niggemeyer

What Can Be Done

The previous chapter may leave some readers with profound gloom or nascent anger. Is this *still* what actually happens in 1985? *Surely* something better can be done! Some professionals will be indignant because they and their colleagues can still be portrayed as ignorant, insensitive or indifferent. Some parents may have "counted their blessings" and risen above the problems outlined. Others will be puzzled at the lack of mention of services which they have come to take for granted.

It is worth remembering that for the majority of profoundly mentally handicapped persons born in the world there is no professional help at all, whether good, bad or indifferent. There is no hospital, no assessment procedure, no family support group, no information, no institution, no equipment. In those countries whose cities do enjoy some facilities, the rural areas are usually unserved; and even in the cities help may be very expensive and patchily distributed.

This chapter will look at what *can* be done: some of the innovations and developments that have been successful over the past few years; some of the possibilities for adapting and distributing good ideas. There is nothing inevitable about such progress. Already it is often the case that what *could* be done is *not* done. And what *can* be done may be omitted, overlooked, be considered inconvenient or be given so low a priority as to disappear in the first round of budget cuts. Some of these considerations will be examined in a subsequent chapter.

No More "Vegetables"

During the past ten years the concept of the child "who will always be a vegetable" has disappeared from the minds of the more enlightened professionals. There remain some individuals with whom extremely little progress is made, and some with regressive conditions which steadily reduce such skills as they have. But the "vegetable" as an immobile, incorrigible object has disappeared. If a person's body and brain are functioning sufficiently to sustain life then they already constitute a system far more complex and finely tuned than anything man has devised. It is the job of the therapist, parent, neurologist and others to tap into this individual network, to try to establish communication, to run some programs, to discover who is inside there.

A number of factors combine to abolish the "vegetable". Considerable progress has been made in the assessment of single impairments and in development-orientated therapy. An experimental attitude towards PMH Zhenya and Okeke has developed, encouraged by progress achieved with moderately and severely disabled persons. Previously there was a tendency to regard PMH Suzie and Salim as a mass of contradictions and impossibilities, so that people neither knew where to start nor had much motivation to do so. Now, a problem-solving approach is used based on the assumption that Ramdas and Maria are "in there", somewhere, and might be willing to meet us and face the world if they were given a reasonable chance.

"Giving them a reasonable chance" may require separately fixing up their hearing and vision, spending a couple of years working on hand control, devising a communication system in which they can understand and indicate options, giving them sufficient motivation to use it; and then watching carefully and waiting patiently for the day when they may shyly draw back the curtain and peep out.

Scientists spend billions of dollars and thousands of computer hours scanning across the Universe for any sign of life or communication from "out there", searching for any sort of pattern that might indicate intelligible communication. When an earthquake overturns a human settlement or when a mine collapses, disaster emergency teams search for weeks in case there might still be somebody alive and trapped "in there". People have spent lifetimes deciphering ancient rock inscriptions and piecing together the evidence of human communication from thousands of years ago. In a comparable way, believing that some worthwhile communication can be established, parents and therapists now use every available means to get in contact, from the warmth

of human cuddling to the computerised analysis of minute electrical currents in the brain.

Interdisciplinary Assessment

In every area of human physiological and psychological development there has been considerable progress in understanding during the past 50 years. One outcome of this is the increase in specialisation, with the unwelcome result that families have often been shuffled from psychiatrist to neurologist, neurologist to speech therapist, speech therapist to physiotherapist, physiotherapist to pediatrician, pediatrician to psychologist, psychologist to special teacher, special teacher to social worker, each of whom has nibbled at the problems, made some notes and referred onwards again. Each specialist may in fact have made a useful contribution to the overall picture, but too often the overall picture is never assembled; or if assembled it is not *used* to indicate the path forward. The need has therefore become apparent for interdisciplinary assessment procedures and conferences in which the observations and evaluation of as many specialists as possible can be put together with the experience of those responsible for daily care and nurture of PMH Suzie.

Apart from the obvious and immediate benefit to PMH Suzie of being reassembled and reintegrated from her component parts, there can be a cumulative professional and parental benefit in this interdisciplinary exchange. If they are not blinded by their own expertise, each specialist can learn something of the professional skills of her colleagues; while parents can pick up verbally the sort of thoughts and suggestions that professionals may be reluctant to commit to writing. The areas of doubt, and consequent need for professional judgements that go beyond the competent performance of standardised tests, is likely to be greater in assessing PMH Maria because at the extremes of disability the usual procedures are not standardised and there is often difficulty both in applying them and evaluating response.

In the scientifically advanced countries there is likely to be an increasing use of "involuntary" techniques of assessing response to stimuli. Electroencephalograms (EEGs) may give evidence that a stimulus has been registered inside the brain although no external clue or response was visible. Alternatively a system may be used that is in fact a robotic version of basic human observation techniques and works according to much the same principle as the lie detector. For example, in the "auditory response cradle" (ARC) used for testing hearing acuity in neonates, the baby's movements, respiration etc. are monitored by the ARC which builds up a picture of the baby's normal range and rhythms of movement; it then supplies a controlled input of stimulus e.g. a sound of particular frequency, and checks whether this causes any detectable blip in the baby's standard patterns.

The use of robotics and computer-assisted response detection is in its early stages, but can be expected to develop very quickly. It is potentially a useful extension to the range of assessment and diagnostic tools, but will cause problems of budget priorities. The choice may arise between installing in a central hospital some computerised assessment gadgetry that is both expensive to install and to maintain but carries prestige and can be a powerful diagnostic tool; or running courses for

community health nurses to improve their observation skills and to provide them with assessment techniques for use in homes with minimal equipment. Traditionally this sort of budget conflict has gone in favour of the expensive gadget.

There is however an increasing awareness of the importance for assessment of evidence accummulated and recorded by non-specialist observers using checklists and guidelines, whether of auditory, visual or mobility response in the home environment. The non-specialist, whether parent or care person, does not have the training and experience of the professional observer but *does* have the advantages of seeing the child relaxed in its familiar environment, having much more time than is available in a clinical assessment procedure, and perhaps also having a greater sustained interest in the outcome. An increasing number of checklists and guidelines for observation and recording is available, covering the full range of child development, with non-specialist observers in mind. (See reference section.)

The last mentioned trend is of particular importance in those parts of the world where there are few specialists or none. There, anyone working towards a better life for PMH Okeke and Zhenya needs to become a committee of experts rolled into one. To make any appreciable impact on the problems it is necessary for such individuals to see their role as one of acquiring and distributing skills and information that will enable families to do their own observation, assessment, programming, therapy and home education.

Improved Counselling

"I used to say to parents 'I'm afraid I have some bad news for you.'" Afterwards some of the parents corrected me. "Who are you to decide that this disabled child is something bad? Just say that you have some news. Parents can decide for themselves what they want to think about the news."
(A pediatrician)

The past ten years have seen an increasing number of parents and parent associations "deciding for themselves" how best the news should be conveyed, and how to gain access afterwards to an appropriate level and quantity of support and information.

The first positive step to improved counselling may be precisely this shift in viewpoint: the professional should understand that it is not so much that "I have the difficult and thankless task of breaking some bad news", but rather that "This family has to *learn* something unexpected, *assimilate* it, and *cope* with it. My task is to *assist* them to do so."

Learning the news about PMH Okeke and Salim may be easier in that their impairments are usually gross and visibly evident: – the parents can more readily believe what they are being told. The professional can with reasonable certainty predict that Okeke and Salim are going to be "different" for life, and will need a great deal of extra care. Just how "different" and how much "extra" are impossible to predict, whether for the professional or for other experienced parents who make take on the counselling role. These facts alone may take some time for people to assimilate. There should always be sufficient time allowed for this learning *process*.

It is not a single event, "breaking the news", which the professional can do at a given moment. It is a process of learning the facts, discovering that there are large uncertainties, assimilating, re-orientating, questioning, reacting. Throughout this process, which may take place over weeks or even years, it is the counsellor's task to listen, speak, listen, supplyinformation, listen, explore possibilities, listen, observe, listen, record, listen, find more information, listen, wait, and then listen some more. Such a commitment of time and attention may not fit into a busy pediatrician's schedule – in that case the pediatrician should either change her schedule or discover ways of sharing the burden with competent people who *do* have the necessary time.

The ideal situation, which no country yet achieves but towards which some are at least aiming, would provide a range of counselling persons, timings and materials, supply of which would be controlled by parents' demands and would be coordinated with the range of assessment services. Counselling persons would include pediatricians, special teachers, psychologists, social workers and parents who had successfully coped with a PMH child and were prepared to give practical advice and support. Access timings for at least some of the counsel-

lors would extend beyond the usual "office hours". Information materials should range from basic introductory pamphlets through specific syndrome descriptions to audio-visual presentation of in-home management skills and techniques, and would be continuously available for inspection, loan or purchase.

To provide adequate numbers and range of competent counsellors requires a large commitment to training and attitude re-formation, which links in turn with the preparation and dissemination of suitable informational literature and audio-visual aids. To prepare information in appropriate format for the full range of parental educational and social levels is no small task. On the other hand, until this task is tackled, and regularly updated, counselling will remain a haphazard exercise.

The course material used in training of doctors, social workers and others involved professionals should also regularly be monitored and if necessary corrected or supplemented by local parents' associations. To achieve their professional qualification, trainees should be required to pass a practical examination of their counselling skills – this will ensure that serious attention is given to it during the course of studies.

The latter focus is particularly recommended for Third World countries which do not yet have the resources to translate and disseminate large and variegated quantities of counselling materials, and where the population may be largely rural and non-literate. There, the sole opportunity for communicating accurate information and advice may be the rare occasions when a rural family brings PMH Okeke to a city doctor. If the doctor's training has included nothing addressing the situation of profound handicap in rural areas, then he will very probably give nothing to the family. Such doctors, when charged with the training of primary health care personnel for rural populations, will have nothing positive to offer on the subject of in-home rehabilitation. It is the responsibility of the International League and its National counterparts to see that something is provided in the professional's training, whereby he *can* give some positive suggestions and advice.

The medium of short radio broadcasts concerning home rehabilitation of disabled children is also worth exploring. Very many Third World radio stations are short of material that is non-political, of general interest and capable of serialisation. The coverage is potentially very broad indeed, since transistor radios have penetrated to every corner of the globe. Short question-and-answer or group discussion broadcasts have a powerful potential for reshaping attitudes and communicating basic management techniques all across the disability field.

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Programming for Progress

Modern interdisciplinary assessment procedures can give some idea of PMH Ramdas's current abilities and potential, together with indications for remediation of physiological impairments. Assessment by itself is however of little value if it does not lead to a program of education and specific skills training. For PMH Zhenya and Maria the priorities for such a program seem to be in the areas of *mobility, communication and self help skills* such as feeding, toileting, dressing.

Progress in these key areas seems to be regarded as significant cross-culturally and internationally. One special teacher was counselling refugee parents of a handicapped child in the Hazara region of Pakistan when he was perturbed to hear the parents refer to the handicapped child as an "animal". He remonstrated with them, pointing out that one should not use such an expression. They in turn were surprised and informed him that in their village all small children are referred to as "animals", since they cannot talk, are not toilet trained, do not wear much clothing and cannot perform simple motor actions.

"In addition to such specialist assessments we must also look to the development of techniques that can be used by non-specialists, and of great importance, to the observations of parents and other care-givers. It is those in daily and nightly contact with profoundly retarded people who have the greatest opportunity to observe how and when they respond to the world around them. In the interdisciplinary assessment we have advocated, this information, too, has a special and important place."

"The use of assessment techniques of the sort described go some way to answering that most frequently heard question: "Where do I start with someone with so many impairments, so many handicaps?" We start with techniques of assessment that will tell us about ***the nature of the impairment*** *and again, we draw on the invaluable information that parents and caregivers can also provide. We must also make a start on considering* ***where the person is within the overall framework of infant*** *and child development, and how the* ***processes of learning*** *that will lead to new behaviours are operating."*

"Importantly, ***there are now techniques of assessment that will enable us to establish with profoundly retarded individuals where in this progression towards understanding they are, where their special strengths and weaknesses lie, and in what direction new experiences should be taking them."*** *Hogg and Sebba*

A variety of approaches have been used to determine exactly what is to be taught to PMH Zhenya at a given moment, and how it is to be taught. It is usual to start with Zhenya's existing abilities, few though they may be, and to work by very small increments towards specific goals. A broad framework is provided by the detailed observational knowledge of the stages through which virtually all young children pass as their abilities develop. This framework, which has been reasonably well established over the past 40 years, gives guidance as to the order in which skills tend to be learnt. The

orderly progress may be disturbed by sensory deficits, or suppressed by severe behavioural problems, and will of course be spread over a vastly longer time scale than a normal child would require to reach a given point. But even if disturbed or suppressed, normal developmental charts provide a useful guideline for deciding what to teach and in which order.

An approach presented at the Conference, attributed to J. M. Gardner and Janine Murphy (1980), involves the following six steps:

- **Step 1:** Identify "core" areas of the curriculum.
- **Step 2:** "Components" – subdivide core areas into component parts.
- **Step 3:** Write "targets" for each component.
- **Step 4:** Devise "standard assessment" for competence of each target.
- **Step 5:** "Task analysis" – break down each target into small steps.
- **Step 6:** Devise a "record keeping" system.

These steps were illustrated by Sebba and Hogg with reference to PMH Peter, as follows:

*"In **Step 1** we identify the main or "core" areas of teaching. For elementary school pupils this might be reading, writing, arithmetic etc., but for Peter we can include here motor skills, self help skills, communication and cognitive skills. These are the areas that the interdisciplinary team of professionals and parents identified as priorities for Peter."*

***"Step 2** involves the breaking down of the "core areas" into parts or "components". To return to our elementary school analogy, we know that arithmetic has a number of components – addition, subtraction, multiplication etc. For Peter in the "core" area of self help skills the "components" might be feeding, drinking, dressing, undressing, toileting, and washing."*

***"Step 3** involves identifying the targets in each component area. For example, for Peter in the "core" area self help and the "component" feeding we may have targets concerned with lip closure, chewing semi-solid food, spoon-feeding and so on."*

"At any given time, there may be many targets for each individual pupil, but it would be unrealistic to expect to teach them all simultaneously. Instead, an attempt is made to teach at least one target from each of the core areas. This might for example mean that Peter has five current teaching programmes, one in each of the areas of fine and gross motor skills, communication, self help and cognitive skills."

***"Step 4** involves describing targets so that agreement between all those people involved in the teaching can be guaranteed. This is the point at which many programmes break down, whether concerned with teaching new skills or with reducing problem behaviours. It may be because the type of skills we are teaching people with profound handicaps are basic living skills which are relevant in a variety of settings throughout the day. This means that more people are likely to be involved in the teaching process than would be the case if we were teaching "chemical equations". Also, the pupil is*

less likely to be able to tell us that some one else has been teaching him/her differently. The following example might illustrate why it is so important to describe targets clearly."

"Peter's teaching target has been defined as: 'Peter will improve his sitting balance.'"

"Teaching sessions occur at home and at the Social Education Centre as follows:

Peter's teaching sessions on sitting balance:

(1) Peter's father carries out Peter's programme every morning as he gets him out of bed. He sits him on the edge of the sofa bed with his feet dangling down and provides support behind him with a cushion. His father puts on Peter's socks and shoes, after which he seats him back in his wheelchair.

(2) Peter arrives at the Social Education Centre. The instructor holds Peter seated on a low wooden bench with no back support and his feet on the ground. The instructor lets go of Peter for a few seconds and catches him each time he leans over.

(3) Peter is having physiotherapy. The physiotherapist sits him on a mat on the floor with his legs extended in front of him until he falls over onto the mat, she repeats this ten times."

"When will Peter's father, the instructor, and the physiotherapist decide that he can sit unsupported and move on to the next programme? When he sits for five minutes on the edge of the bed without support under his feet but supported behind him? When he sits on the wooden bench unsupported for two minutes? When he sits on the floor unsupported with legs extended for one minute?"

"In this example, Peter is expected to perform different tasks by each person teaching him. Also, each person may have a different view of when Peter has been successful and is ready to move on to another task. In order to make our programmes as successful as possible we need to specify clear and precise teaching targets. An example of a target for the situation I have described might be:

Peter sits on the floor with his legs extended without support for two minutes ten out of ten times."

"This standard target specifies both the conditions under which Peter is expected to do the task and the criteria for success."

***"Step 5** involves the breaking down of each target into smaller steps. This process, called task analysis, will I'm sure be very familiar to many of you. Taking the example of Peter's core area of self help skills and the component of feeding, we might have a target on spoon feeding. This could be broken down into smaller steps such as grasps spoon, puts spoon in bowl, scoops food onto spoon, lifts spoon to mouth, opens mouth, puts spoon into mouth, closes mouth, removes food from spoon, lowers spoon to bowl and so on."*

"The order in which steps are taught has to be decided. Peter may require work

on the closing mouth and grasping spoon steps on the basis of his assessment information. Depending on the individual the same task can be broken down into more smaller steps or fewer larger ones. When you next wash your hands, try counting the number of steps involved. This may give some indication of how complex even the most basic skills may seem when analysed."

***"Step 6** refers to the recording of the teaching sessions. Recording is tackled in a veriety of ways depending on the type and amount of information considered to be important.*

Record keeping is arguably more important with people with profound handicaps as progress is often very slow and subtle changes may pass unnoticed by people in daily contact with the individual."

"However, it is important for the interdisciplinary team to agree on the amount of detail that can be realistically recorded over long periods of time. If there is too much paperwork, professionals or parents are more likely to abandon the recording altogether."

Sebba and Hogg

Achieving Progress

Having reached a clear definition of what PMH Maria is to learn next, and having coordinated this among all the people having contact with her, it remains to *effect* the learning process. Maria has to be made aware of what is wanted and be motivated to learn and perform. In the normal child, learning appears to take place "naturally", stimulated by curiosity and a desire to exert some degree of control over the environment. With PMH Salim this is often not the case, or he may have had his curiosity extinguished through negative experiences.

Various teaching techniques may be employed, singly or in combination. The required action or skill may be modelled ("See Mummy put her foot in her shoe! Well done, Mummy"), then physically demonstrated ("Now Maria gets her foot in her shoe! Well done Maria"), with suitable congratulation, reward and repetition ("That was fun! Let's do it again!") Physical prompting may progressively be diminished, and more action demanded for a given reward. The "natural" reward of *completing* an action, *achieving success*, has advantages over more material rewards.

It is not possible in a conference report to do more than broach these few ideas of teaching content and method. Manuals for in-home parent-directed rehabilitation are becoming available in increasing number and quality, geared mostly towards the moderately and severely retarded person. Many of the methods can be used directly with PMH Okeke and Zhenya. (See Reference Section)

The techniques of behaviour modification and a tightly controlled approach to learning have been very productive with PMH Suzie and Salim when their teachers had had little or no measurable success with any other approach. It needs, however, to be pointed out that there are other possibilities for inter-personal exchange on a less one-sided basis, though the results may be less readily verifiable. Perhaps there is more to life than pushing pegs into peg-boards and achieving the next step prescribed by the psychologist. Speech, symbols, pictures and rewards are one medium of communication; music, to take an example, is another medium quite as rich and variable. What educational goals are achieved by bathing the bruised psyche in music? Who knows? PMH Zhenya should perhaps be allowed a deliberate quantum of non-measurable educational experiences until the neuro-sciences can give a clearer picture of what is going on inside her head.

Communication and Social Behaviour

Among the various areas and targets for learning, Communication and Social Behaviour are crucial to the establishment and development of human relationships. They are indeed integral to the whole process of teaching PMH Suzie.

The baby and young child normally comes equipped with a very powerful communication device and monitor, based in a few principles such as "If I scream, somebody comes". The normal baby rapidly develops a series of gestures and facial movements in response to different inputs, which are interpreted by the primary care-giver, usually the mother, with more or less accuracy. In the case of baby PMH Ramdas this development may be very slow or non-existent. The lack of diversification may cause problems of interpretation. The "monitor", by which the baby understands that the required effect has been achieved and therefore she can stop yelling, may fail to function in the case of baby PMH Zhenya. For lack of early experience of positive communication and rewarding social behaviour PMH Maria may fail to persevere beyond the level of screaming. Undifferentiated screaming is in the long run ineffective as a form of communication in that it tends to secure diminishing returns from care-givers, leaving PMH Maria still hungry, uncomfortable, lonely, or whatever produced the need to scream. Other action-producing communication methods such as PMH Salim banging his head on the floor are also counter-productive if over-used, since the reaction of care-givers may be to tie Salim to his bed or chair in order to prevent damage. Not surprisingly, disabled children who fail to establish some effective means of making their needs understood tend to develop problem behaviour. Their life consists of a series of physical drives and discomforts many of which they can neither satisfy by their own efforts nor communicate to those who could help. This situation may go on for years.

In particular it may be suspected that there is a close connection between disturbed communication and disturbed behaviour. I will illustrate this in three examples:
a) Very young deaf children are far more aggressive than their contemporaries who can speak, but as soon as communication becomes possible the aggressiveness decreases.
b) Non-speaking mentally handicapped children are often strongly aggressive and suffer from sleep disturbances. As soon as these children learn to communicate, e.g. through speech supporting gestures, these aggressions wear off.
c) Finally, imagine that you are not understood. In the beginning you make great efforts to express what you want to communicate; then you speak louder; in the end you become angry even if you realize that there is no reason for this.

H. Adam

With normal children, families pay no more than passing attention to the early non-verbal levels of communication because the expectation is that normal speech will develop. In the case of PMH Okeke, where speech shows no signs of developing, the non-verbal measures assume a much greater importance. The field of non-verbal communication was first entered by deaf persons and their teachers, and unfortunately developed into a battleground between those who believed that normal speech and sign communication were mutually exclusive or at least antithetical. During the past ten years it has become clear that the battle was pointless. Normal speech is supported by gestures. There is some evidence that the development of speech is facilitated by the development of hand movements, and vice versa. At the same time it has become apparent that what is important is *communication* skill, of which speech is only one variety.

As evidenced in Dr. Adam's detailed paper, the number and variety of non-spoken communication methods and systems has grown rapidly in the past few years, to the point where "speech therapists" should perhaps be relabelled "communication therapists". Speech and writing are among the most complex of human activities in their potential range, and even the normal six-year-old attains a depth and specialisation of language vastly in excess of her everyday needs. Starting at the other end, with a minimum list for everyday purposes, is a process familiar to travellers in foreign lands, which is largely the situation of PMH Maria as she makes her way through life.

The difference is considerable between Maria understanding and communicating

When deciding which communication system is most suitable, consider the following four points:

(1) Is it possible to communicate verbally or is it only possible to communicate without speech?

(2) If speech is not possible, should natural movements, i.e. speech supporting movements, be used – or a symbol system such as pictures, pictogrammes, Bliss and writing?

(3) If speech is not possible and the use of movements proves to be of little value it must be decided what symbol system is most suitable.

(4) When it is clear what communication system should have a priority, contents and methods should be considered. The child's interests and needs must be the guideline. Many severely handicapped children are almost only interested in edible things. Formerly this was used in behaviour therapy. Today we try to teach the children that they themselves can accomplish something through letting them ask for various foods. In the behaviour therapy the child was asked to say "apple" – and when the child repeated the word the therapist was happy and awarded him a spoonful of chocolate spread. Today we try to achieve a form of communication, asking "what would you like?". The child points to the symbol for apple and gets an apple.

H. Adam

When dealing with an individual child and trying to decide what communication system should be used, it must never be a question of either/or. Spoken language on the one side and a sign system on the other should be considered extremes of a continuity. The input may be found in different stages of this continuity. A spastic child may, for example, be able to understand speech when the context is clear and the speech is supported by gestures, but his spastic paralysis prevents him from speaking properly and using his hands to make signs. This child may, however, be able to communicate using pictures, symbols or writing. It is completely acceptable to use different systems for the same child.
The spoken language should always have a priority – parents and teachers should keep talking to the child and encourage him to talk. But it may still be useful for children who are able to learn to speak to use gestures in support of their speech. This may help avoid breakdown of communication.

H. Adam

nothing, and Maria understanding and communicating a *basic dozen* or so words/word-groups: Maria (I, me), Yes (good, I like it), No (forbidden, I don't like), Eat (hungry), Drink (thirsty), Mum, Dad, Come, Wash (bath), Toilet, Bed (sleep, tired), Put clothes on, Put on Jacket (coat), put on shoes, Going out (going for walk), Going by car (bus, vehicle).

Physical gestures to communicate the above list are available in most countries, though the gestures are not necessarily all similar. Some efforts at standardisation of basic pictograms have been made in international airports and in primary health care outputs. It seems likely that this communication field will diversify a great deal more before the optimal approaches are discovered for PMH Maria and her friends. But even a far – from optimal approach is likely to be a great advance compared with silence and blank incomprehension.

Personnel and Training

In order to progress beyond what usually happens in practice and to achieve some of what *can* be done, a number of factors are needed in combination: 1) a public recognition that to give adequate care and education to PMH Okeke is a skilled job demanding intelligence, perseverance and fine judgement; 2) a scale of remuneration consonant with this recognition; 3) basic training and regular inservice refresher courses of a suitable breadth and intensity.

Factors militating against this achievement are: 1) PMH Okeke is often looked after by his own family, who have no special training and in most countries receive no external help or remuneration; 2) many of the central skills involved, e.g. feeding, toileting, dressing, promoting movement and speech, appear to be among the most elementary of human activities; 3) in many parts of the world the necessary involvement with toileting and elimination sets this work in a category of "unclean" jobs which can be performed only by the lowest stratum of society; 4) the progress potential, while now beyond doubt, appears to be of marginal utility in the public mind; 5) the welfare field world-wide seems to have entered a new ice age.

Of the three positive factors needed in coordination, only the third seems to be readily realisable in the present state of public opinion and economics. The increased professionalisation of the entire welfare field has both caused and reinforced a willingness on the part of Western governments to promote skills training. In the Third World there is a large, undifferentiated demand for "training courses", often uncoordinated with actual job opportunities. In both worlds it will be one of the tasks of the trained personnel to fight for improved conditions, remuneration and recognition of their skills.

The severity and combination of disabilities in PMH Ramdas are such as to make his needs different to those of PMH Suzie, who differs again quite distinctly from PMH Maria and so on. What they have in common is a lack of independence for everyday living activities. Personnel training therefore has as one of its primary objectives to enable caregivers to assist in these everyday functions in a deft, kindly and comfortable manner while always encouraging PMH Salim to take a greater part. A second major objective is to learn to collaborate with other people involved in the life of PMH Zhenya, whether her immediate family or other professionals. In either case, teamwork is of the essence.

PMH Suzie needs to be moved from lying on one side to the other side regularly in order to avoid discomfort and bedsores. This can be done easily but negligently by pulling her over like a sack of potatoes, leaving her clothes twisted

Could I also stress the fact that the lack of financial resources, in itself, need not necessarily be a total obstacle. The development of services for mentally handicapped people is a labour intensive matter, and what seems to be needed – both in the Third World and the developed world – is to increase the level of training. But training itself is also a labour function, and in a world with so many millions of people unemployed it must be conceptually possible for us to develop services for mentally handicapped people without being totally frustrated by lack of funds. It is a matter of having the will and determination to make it happen.

D. Wigley

In the training of personnel, we have therefore to make room for exchange, dialogue and listening to others. There is always a double tendency: try to find out from others the solution to multiple difficulties – "We are not equipped for that child" – "other structures might be better adapted" and, at the same time, criticize suggestions and ideas proposed by others.

Since the work is hard and full of contradictions, conflicts are unavoidable – and sometimes beneficial, but sometimes also can do harm when they arise from more personal problems or when they distract the attention from the real task to be accomplished.

Dr. L. Georges-Janet

and pillow disarranged, with slight but cumulative bruising. Or, by taking thought and careful observation, it can be done with friendly words, collaboration by Suzie moving whatever parts of her body she can, rearrangement of clothing, placing of pillow and cushion to support head, neck or whatever limb needs support.

PMH Zhenya is capable, though very reluctantly, of tottering ten steps very slowly with support on both sides. It is a great deal quicker to move her about in a wheelchair. The care assistant in training needs to face the implications and conflicts of an institutional timetable which may allow little opportunity for the ten tottering steps, or a domestic household situation where there is plenty of time but may be no second helper to give support.

PMH Maria is doubly incontinent, has not learnt to indicate her needs for elimination, has digestive problems that result in a permanently unpleasant body odour, and is blind. The trainee professional care giver needs to discover ways of overcoming or disguising natural distaste and developing a pleasant, progressive routine of personal hygiene, perhaps with spoken commentary naming body parts by turn, promoting cooperation and human dignity.

PMH Salim can feed himself to the extent of putting his fingers into mushed food and transferring them to his mouth, though the quantity transferred is insufficient to sustain him. Salim will take liquid from a spoon but prefers mush either from his own or someone else's fingers. The trainee needs to learn the nutritional intake and balance required for reasonable health, ensuring adequate nutrition

while building on Salim's existing ability and interest.

PMH Okeke is athetoid, has severe hearing loss and can manage only two distinct signs to indicate "toilet" and "hungry/thirsty". His preferred activity is to sit for hours in front of a television. The trainee care-giver needs to give careful consideration to the development of further communication, in consultation with the visiting teacher.

In practical work with the above PMH people the trainee needs to learn to judge the optimal physical closeness and professional distance, to know something of the physiology of movement, nutrition, the normal and abnormal digestive system, the psychology of dependence and of learning processes. The trainee needs to learn how to preserve her own physical and mental well-being; how to be involved intimately, while still observing and recording professionally; how to maintain a progress-orientated perspective and continuity of purpose with co-workers; how to be flexible, observant and imaginative in the face of each different individual, bearing in mind that the profoundly handicapped person is capable of taking joy in the humblest activity but capable also of depths of misery. Such training evidently requires a high degree of supervised practical work with subsequent reflection and discussion.

Apart from the time required for personal hygiene, nutrition and so forth there are a lot of hours in each day, whether lived at home or in a communal situation. The teaching targets and communications objectives previously referred to must be made familiar to the basic care-givers as

One of the difficulties of training in this field is the absence of any "recipe" to deal with the diversity of individual cases.
Our objective is to compare experiences and try to make personnel watchful and active in complex situations, able to identify errors and difficulties, able to perceive efforts to try to communicate – even by such archaic means as exploring the neighbour's plate, throwing of food or refusal – or impossibility – to tolerate any frustration.

L. Georges-Janet

In fact, training must not be based on a theoretical level but on an analysis of the learning potential of all activities.
For example, a walk outside will provide learning of opportunities (clothes and body), its aim, the movement, the constitution of a group, the change of place, its interest in the observation of a different environment and different circumstances (reactions to variations of temperature, of the wind, the sun etc., ...), its interest for the adults of the group (get out of confinement, go towards ...) the interest for new materials one can discover – sand, earth, leaves, that can be used when coming home.
This analysis of what the period of activities can bring must be thought about with the persons involved and follow their suggestions.
It is from such a basic analysis of simple

Learning to start with a simple, joint project, to evaluate its results and thereby start a mutual exchange between parents and professionals, is a difficult phase of each training which directly involves the personality of each individual. Therefore it is necessary before the beginning of training to choose the kind of persons really fit for this profession.

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situations that personnel can learn how to propose new activities and how to adapt manual or bodily activities to people who have severe physical difficulties or who are very unsteady, and can discover new ways of relating and, therefore, communicating.
Learning to build a common project, modest at the beginning, to evaluate the results after a certain time, to proceed together as parents and professionals through a real exchange, is a difficult stage in the training process, in which the personality of each one is directly involved.
This is why selection of staff is essential at the very beginning, in order not to enrol in such professions personalities that are too frail for such a task.

L. Georges-Janet

well as to the professional teachers. Opportunities for communication must be created, taken, recorded, analysed and built upon. This can hardly be effected without training, and even after training it does not automatically take place. A good deal of support and encouragement for the front-line workers is recommended, whether that person is parent, sibling, volunteer helper or professional care-giver.

Learning to work in a team involves imagining situations from the point of view of PMH Ramdas's family and of other professionals less immediately involved with Ramdas, and responding to their needs and inputs. This involves listening and observation and the effort of empathy. To some extent these capacities can be trained; but undoubtedly by the time people reach the age of 20 there are some who are better endowed than others with these capacities.

Integrated Regional Planning

In a number of countries efforts are being made to see mental handicap and its problems on a broader canvas. Such schemes have not come about specifically in consideration of profound mental handicap, but they are broad enough to include all levels of disability. They arise partly fom the understanding that mental handicap is not a single difficulty to be dealt with at a given place and time. Instead, it is a feature of human life, affecting thousands of families in every aspect of their private and public life, scattered fairly evenly throughout the community.

In the absence of Integrated Regional Planning (I.R.P.) mentally handicapped people disappear down the gaps between education services and the health department; they fall through the social welfare network, because they live in the wrong place, or are too big or too small, too disabled for one facility, too able for another. Money is available to pay for X service in Y locality, but not for P service in Q locality, unless regulations Z are in force in which case PMH Suzie does not qualify because she is too old, too fat and too difficult. Equipment E is available at Depot D, that would certainly assist Suzie; but only if her family can find a house designed with a sufficiently wide corridor and stair-well; and they will have to hire their own lorry to fetch the equipment because the Transport department say it is a Health matter and the Health department say that Depot D is outside the area for their vehicles to operate.

In the case of PMH Suzie, I.R.P. could at its best mean that the resources of a whole region are *known and available for the purpose of solving Suzie's problems,*

In Sweden they regard ***handicap,*** *as being a relationship between a disabled person and his or her environment, be that the physical environment, the social environment or the psychological environment. We, as individuals or as a community, may not be able to do much about the precise disablement afflicting the disabled person, but we can do something about the environment, whether it be the physical, social, or psychological environment. To this extent* ***our success in preventing disablement from turning into a handicap rests on our ability to control the environment and as such it becomes the responsibility of the community as a whole.*** *On this basis the challenge to avoid and to minimise handicap, arising from disability, both for the individual and for the family, is one which rightly must fall on the community.*

D. Wigley

rather than a few slots being available in one place and time, into which she does not fit. "Integration" can mean several things: a) that services are mutually aware and cooperative, instead of the usual picture of mutual ignorance and antipathy; b) that the same services are available to PMH Suzie as to everyone else, with any additional aids she may require; c) that PMH Suzie and her family are seen as full members of their local and broader communities. "Planning" also bears more than one message: i) I.R.P. is not something that happens overnight, even by decision of a dictator. It is a goal and on-going target to be worked towards, planned and re-planned over a period of years; ii) Planning and re-planning requires epidemiological data and review, so that the services which first met Suzie in her early months are not taken by surprise to find after a dozen years that she is entering her teens and has a different set of requirements.

The "All Wales Strategy for the Development of Services for Mentally Handicapped People", which is now in the process of being developed and implemented, is based on the concept of care within the community rather than institutional care, and for this not just to be a theoretical concept, but to be put actively into practice. It is a ten year strategy aiming to move away from long term hospital, and it involves the integration of education, housing, employment ect., with an emphasis on community. Clearly it is more difficult for those who are profoundly disabled to be integrated in this way, but that is the objective of the All-Wales Strategy.

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I.R.P. can of course be attempted in any region or country, but it rather assumes the existence of very substantial resources which are uncoordinated merely because nobody has yet given high priority to solving inter-sectoral problems. It assumes that there *are* health, education and welfare services, architects, designers, transport facilities, manpower deployment agencies, and that these services function passably well for the bulk of the population. In many developing countries such assumptions are hardly justified.

A Case of "Integrates Regional Planning"

The Director, Social Services, South West Region, Republic of Ruritania; 5 million population increasing at 3 % yearly, finds himself with 10 staff having some training relevant to the rehabilitation field. There are social workers, 1 psychologist, 2 teachers of the deaf, 3 physiotherapy technicians, 1 vocational instructor for mentally handicapped adults, and a part-time paediatrician. The Social Services budget will cover their salaries plus a very small amount of equipment and travel expense. The Director has an option to use parts of hospitals and community centres in the five major towns in S.W. Region.

Approximately 1% of the population is perceived by local people as being disabled, i.e. 50,000 persons. Of these, 70% live in the rural areas, whereas Government services do not extend beyond the towns. The Director knows that with sufficient effort he could locate about two-thirds of the town-dwelling disabled persons, i.e. 10,000 out of the 50,000. Among them are some 2,000 confirmed beggars, either blind or physically disabled, who have been surveyed and questionned by a local students organisation. They are not interested in rehabilitation services. Another 2,000 are elderly people who have become deaf, blind, physically disabled or senile; neither they nor their families expect anything to be done about this which is seen as a normal and inevitable feature of old age. There are also about 200 disabled persons already usefully occupied and not requiring rehabilitative action.

Among the remaining 5,800 there are 3,000 children aged 4 to 15 years, (2,500 boys, 500 girls) who could gain considerable benefit from special education or from physiotherapy, prostheses and normal education. Among these, 2,300 of the boys' families and 50 of the girls' families would be prepared to make the effort and meet some of the expenses of sending their child for treatment and schooling.

There are 2,000 young and middle-aged adults with various severe disabilities, most of whom would like to receive some training, e.g. in handicrafts, by means of which they might earn some money. There are 400 who during the previous 20 years did in fact receive some such training in Government institutions. And there are 400 profoundly retarded and multiply handicapped persons of various ages. Families of 380 of these people accept that they are profoundly handicapped for life and there is nothing to be done about it. The other 20 make some efforts, bothering the Director, Social Services, and travelling about the region visiting shrines and quacks.

The Director, therefore, can locate about 4,000 severely disabled children and adults who want treatment or training and will make some effort to secure it.

He was rehabilitation facilities which with the greatest effort and goodwill (neither of which is present) could handle about 300 persons per year. Demand is increasing steadily with population growth and urban drift. The more success his staff achieves, the greater the demand from families who were previously unaware that anything could be done. The Government's policy, understandably, is to concentrate its meagre resources on the more promising areas of need. To justify his present budget the Director needs to report each year that at least 20 disabled young persons completed their education and were placed in jobs, a further 50 adults completed vocational courses and began contributing to their family income, and a further 200 cases are in the pipeline which will lead to similar success over the next few years.

The Director automatically doubles all success statistics that he submits to his superiors, but he has no reason to expect his budget to increase. The international loan consortium that supports Ruritania has prescribed austerity measures, and Social Services does not produce anything to help the balance of payments. The Director also has responsibility for orphans and widows in his Region, he is supposed to be finding some solution to the problem of beggars and madmen in the streets, and there is an alarming upsurge of child abuse, prostitution, gambling, drunkenness and drug addiction that all fall to his lot.

The Director, Social Services, is a kindly and reasonable man, placed in an unreasonable position. He is embarassed to find that he has nothing to offer the dozen or so families with profoundly handicapped members who take turns to invade his office. He has been driven to make a standing arrangement that after ten minutes his clerk should interrupt with an urgent message summoning the Director to Government headquarters, in order to get away from those families.

What Should Be Done?

There will be some people for whom this chapter is redundant, following as it does after the chapter "What *can* be done?" They would answer simply that everything good that *can* be done *should* be done. In one sense this is true, but it is an "ideal" position which does not correspond with the realities of life in any country. Among all the good things that *can* be done, some seem to be mutually exclusive or aiming in opposed directions; almost all depend on resource allocation priorities; the accessible resources are seldom sufficient to carry out more than a few of the good possibilities for *some* of those needing them.

To begin to answer the main question in this chapter it must be subdivided first into a series of ancilliary questions: Why should anything be done for PMH persons? What human and financial resources should be provided, and by whom? And so on.

Why Should Anything Be Done?

There are moral / humanitarian, religious and philosophical arguments, pragmatic and economic arguments, biological/scientific arguments and artistic/aesthetic arguments for helping PMH Suzie and Okeke. Some of the arguments are similar or overlapping. They will be outlined briefly.

Moral/humanitarian/religious/philosophical arguments

There exists a need, felt and evidenced by a fellow human being and her family, which we can go some way towards meeting: we *ought* to do so, because therein we reaffirm an important feature of our common humanity. We ascribe worth and value to our fellow human being, without regard to her apparent level of achievement or capacity to give in return. We postulate that on the level of the soul, the spirit, the human/divine essence of PMH Maria, she is in no way less valuable than any other person. We obey and fulfil the humanitarian/religious precept to love; so treat PMH Ramdas as we imagine we would like to be treated if we were in his position; or in the position of his family.

Furthermore, in a world where voters and taxpayers support Generals who seriously plan for megadeath contingencies and multi-megadisabilities, the tender care and nurture of helpless and harmless fellow beings constitutes a sign-post pointing in a different direction. While it appears currently to be beyond mankind's capacity to shift resources decisively away from armaments and war towards providing a better life for people with social and economic disadvantages, its at least beneficial that some sign-posts exist as reminders that other values are possible, even attractive.

We respond to the need on a "future reciprocity" basis, because we may ourselves one day be in need, be disabled, weak, frail and elderly. We wish to affirm now the principle that the stronger should help the weaker, in the hope that this principle may be applied in our own time of need. We allocate resources also in order to restore the family to economic productivity, since in the long run it is cheaper to do so than to have family members removed from their normal employment by the exigencies of caring for PMH Zhenya. We foresee the serious difficulties in drawing a line and refusing to treat or help PMH Salim who falls below that line: once Salim and all the others below that line have been removed, there will be a tendency to redraw the line to eliminate another sliver of the population, and so on with incalculable results, ending up with a "superrace" guilty of genocide. By contrast, care systems function better for everyone as a result of the design features and interprofessional cooperation necessarily brought about by including the most profoundly handicapped in service provision: they are a means of testing a system for flexibility and for compassion.

Biological/philosophical/scientific arguments

Our response to need, to crying, to gestures of appeal, to physical attachment, may be conditioned on the biological/physiological level, neglect of which can lead to a dangerous and unwanted desensitisation. There are very large areas of ignorance concerning aetiology and appropriate management of Okeke's and Ramdas's profound handicap. The scientific method suggests that nothing should be discarded, no evidence should be neglected or ignored, until our ignorance is enlightened. We do not know whether we can "do without" the PMH members of the human race; nor do we know whether scientific investigation will produce methods for relieving a good part of the present impairments. We have no means of measuring "quality of life" as perceived by PMH Zhenya and Maria, and therefore are on shaky ground if we decide that their quality of life is too low for that life to be worth sustaining.

Artistic/aesthetic arguments

Apart from the "necessary" activities of the human race in providing itself with food, shelter and companionship, there are innumerable "unnecessary" and economically non-productive activities such as setting and solving crossword puzzles, painting sunsets in oil colours on canvas, climbing mountains "because they are there", cultivating rose gardens, making music, designing fashion wear, all of which are chosen as articial activities performed for their own sake, on artistic/aesthetic grounds. The preservation and nurture of PMH Okeke and Suzie is also to some extent an artificial exercise without which they would die, carried out because it is enjoyed and the challenge is felt to be worthwhile. Unravelling the puzzle and mystery of PMH Ramdas and imposing a print and pattern upon his mind are activities carrying their own reward.

Arguments Deniable

The above outlined arguments can be dismissed or denied by anyone who feels no responsibility for the human race beyond oneself and one's immediate family. In practice this appears to be the position of very large numbers of people, whether in Western cities or developing countries, for whom their social context promotes little or no sense of community and communal responsibility. Even where some obligation to one's neighbour is admitted, it may well fall far short of caring about the neighbour's profoundly handicapped child.

That the arguments are deniable does not mean that they should not be advanced. It is questionable to what extent people can be induced to better action by exhortation, but at least there should be vigorous advocacy of high or ideal standards in order to nail down one end of the spectrum and prevent the whole line from slipping. In particular a body like the ILSMH exists to advocate a better life for mentally handicapped people and their families, and it should not be diverted from that task. However, the task can best be performed by coming to grips, from time to time, with the unpleasant realities of public attitudes and their underlying rationale. Many of the advocates within the ILSMH have a personal and professional interest or stake in the future of mentally handicapped persons. It is advisable to separate that personal interest from the question of broader interests in order to see how the arguments and priorities may appear to Government officials in Finance and Planning, to whom appeals are addressed continually from needy and interested groups of every sort and description.

Appeal is often made to the concept of "Human Rights" and the need for PMH Salim and Maria to enjoy the same rights, or appropriate equivalents, as everyone else. "Human Rights" are an outcome mostly of the humanitarian arguments previously outlined for benefitting other people. They are useful as a sort of program or objective towards which Governments and communities can commit themselves. In the developing countries and indeed for the majority of the world's population, achievement of basic "rights" to food, shelter, education, peaceful existence, freedom from coercion etc. is rather fragile even for able-bodied persons. In those circumstances, regretably, the needs of PMH Okeke and Zhenya have low priority.

In time of national scarcity the notion that the Secretary of State for Production, the farm labourer and PMH Suzie are all of equal human value *and* should each be provided with the necessary functioning resources, is not so readily perceived. While the general equality of value may be admitted in theory, the functional value of the one who produces food appears to

be superior to that of one who merely consumes it. This may be a mistaken or unworthy perception, judged by some lofty external moral yardstick. In practice however there are very few people who do consistently accord equal value to themselves and their neighbour regardless of functional qualities.

In the case of babies, who begin completely helpless and whose functional worth, being largely confined to sentiment and entertainment value, is marginal, greater value is attached to their *potential*. When a baby is profoundly handicapped, both its present and potential *functional* worth tend to be marginal. This needs to be borne in mind when attempts are made to influence attitudes. In the case of most single disabilities, even of some severity, the argument is used that persons with those disabilities can be producers and contributors if they are given the means to help themselves. Such an argument is an interesting and appealing document entitled "A Full and Rich Life: A Human Right for Profoundly Handicapped Children", written by Karl Grunewald and produced by the National Board of Health and Welfare, Sweden, was circulated at the Madrid Conference. Its main thesis is that PMH Maria's life "is worth just as much as that of a non-handicapped child. The type and degree of handicap does not alter the value of the human being." In the course of its arguments it states, "The fact that one child understands 'somebody will come if I scream' is in principle worth just as much as another child understanding the connection between waterfalls and electricity." Again, this "principle" is more in the nature of an ideal to be aspired to rather than practical guidance in an imperfect world. The *survival* of the child who screams *depends upon* the intelligence of the child who understands hydroelectric generation. The reverse, so far as we know, is not the case, although one could argue that the *"humanity"* of the more able depends upon their treatment of the less able.

The equipment and techniques used in modern premature baby units, which ensure PMH Okeke's survival, were not devised by people of average and below-average intelligence. In practice, life in virtually every type of society incorporates the daily exercise of dicrimination between greater and lesser competence in other people. One cobbler's shoes are stronger and fit more easily than another's. One cook's food is tastier than another's using the same ingredients. A large part of the global advertising industry, engaging a far greater total of human, financial and technical resources than the global rehabilitation effort, is devoted to persuading people that one cook is tastier than another, one cobbler more comfortable than the other, reinforcing the tendency to choose and, by choosing, to reject what is perceived as inferior. This phenomenon is of course profoundly divisive and militates against the virtues of humility, love and temperance which are preached by the major religions of the world. It is difficult however to imagine in practice any substantial reversal of this tendency, starting with the world as we know it and human beings such as we are.

In fact, parents of PMH Ramdas and advocates for PMH Salim and Zhenya are continuously engaging in choice when it comes to professional services: this pediatrician is more sympathetic than that one; this care assistant is clumsy, while

that one is competent but arrives late for work. Why should a care assistant be criticised simply because she has less manual dexterity or a faulty judgement of the time required for travelling to work? "In principle, a clumsy care assistant is worth just as much as a dextrous care assistant." But that does not stop the advocate from being irritated with the clumsy girl and setting a higher value on the competent one. Once this argument reaches the point where "we are hiring professional skills, therefore we should not have to put up with incompetence", the professional person has been depersonalised and dehumanised, and this does no good in the long run to the cause of PMH Salim and Zhenya.

Who Works, Who Cares?

To agree on what *should* be done is no guarantee that in practice there will be people available to do the work and resources to pay for work to be done. Especially with PMH Salim and Maria their care and nurture requires love and patience, sometimes for little immediate reward. These qualities can be *encouraged* by generous provision of staffing and well-designed environment, but love and patience hardly can be purchased and may fail to be generated spontaneously.

This ultimately can be the limit on provision of services. In response to pressure a given nation or community may make sufficient money available to provide all sorts of material and personal assistance for PMH Suzie and Ramdas. But unless their care and nurture is generally regarded as a worthwhile, praiseworthy, enjoyable and fulfilling job, there will be a deficiency of people prepared to perform it well, or to pay for it to be done. The more usual situation in fact is that existing provisions have low priority, low status and inadequate funding, so that the work is practically impossible to carry out properly even when staff attitudes are positive.

In practice the attitudes of everyone connected with PMH Suzie and Okeke tend to be rather ambivalent. Most parents seem to feel, at times, that it would not be such a bad thing if their child were to die.

A similar feeling is present among many care staff concerning their charges, part of the time. These feelings may cause guilt and withdrawal, and may in fact be converted into strong demands that "someone" *must* supply the tenderest lovingkindness to PMH Zhenya. There *should* be *someone* who has all the *right* feelings of tenderness and love towards poor little PMH Salim, even if I cannot produce those feelings, or cannot do so consistently.

But there is nobody, in an imperfect world, who consistently has both the best attitudes and actions. It is comparatively easy to have fine feelings when there is no necessity to demonstrate them in practice. Equally, at the other end of the spectrum, those who advocate that PMH Maria should quietly be put to death may find it more difficult if they themselves were called upon to administer the fatal overdose.

Death and Life Meaning

There is a practice traditional in many countries and perhaps now increasing in the West, that when people become old and feeble they kill themselves or are put out to die by their family. There is an increasing awareness in Western countries that the "right to die" needs to be protected: that if one suffers a deterioration that would normally lead to death, one should be protected from medical technology that would keep one's body functioning long after any will to live or purpose in living had ceased. Many people if they knew that within a short while they would suffer severe brain damage through an accident or stroke, leaving them functioning at the level of PMH Ramdas, would kill themselves outright.

Among the major religions and philosophies of the world there is a multidimensional spectrum of attitudes towards death, linked with evaluation of the meaning and purpose (if any) of life. Throughout history PMH Suzie and Okeke have been rather precariously situated at different points along this spectrum. The current conventional wisdom of the West is sharply at variance with popular views in other parts of the world on this topic. During the past 200 years the cultural values of the West in every area of life have been imposed on the rest of the world by both the medium and the "message" of modern technology, an imposition that has been very deeply and almost universally resented. The depth of penetration varies considerably, according to factors such as urbanisation, access to mass media, education etc. The cause of PMH Zhenya and Maria is unlikely to be helped by any attempt at imposition of Western views and values on the rest of the world: even if the Western views and values were in any sense "better" than those found elsewhere, imposition is seldom an effective longterm strategy for dissemination. This is not the place for any extended examination of the world's attitude to life and death. But it is worth pointing out that approximately 1 billion people live in countries where belief in reincarnation colours attitudes to the present life, and death is to some extent viewed as a revolving door that leads on to another in a cycle of lives. As many as 2 billion people live under the influence (whether accepted or rejected) of the major monotheistic religions, which teach that conduct in the sole present life is crucially decisive for destiny in some sort of future existence. At least 1 billion people live under the influence of philosophies teaching that life has no divine or external meaning; mankind must work out its own meanings and purposes, if any; death is final for the individual, but the human race as a whole is progressing towards some improved sorts of social systems and living structures.

Perceptions of PMH Suzie, Okeke, Salim, Zhenya, Maria and Ramdas vary very considerably between these billions of people. For some, Ramdas is profoundly disabled because of misdeeds in a previous incarnation. This can produce negative attitudes, but not inevitably so: it is possible to believe that a soul whose previous lives are full of action and command *needs* at least one life of humble dependence and harmlessness in order to achieve enlightenment.

In their different contexts Maria's and Salim's profound disability may be believed to constitute a test of their families' and communities' character: an opportunity to develop compassion, to show fortitude, to exercise imagination. In PMH Zhenya's context perhaps the question of *meaning* does not arise in considering her disability: it has no meaning. It is an abnormality occurring with a given statistical frequency. Zhenya will consume *x* quantity of food and shelter, and will require *y* person-hour of care during an average lifetime.

Fulfilling One's Potential

"To help people fulfil their potential" is the goal of many educational and rehabilitative programs. In general terms there is much to be said in favour of this; but for profoundly handicapped persons it requires closer examination. The fact that it is considered appropriate for many other sorts and conditions of people does not guarantee that it will be appropriate for PMH Suzie and Salim. For a start, it is an unattainable goal: even Prime Ministers, Olympic medalists, prima donnas, Trappist monks, all wish for another nine lives to do all the other things of which they are capable, and the ordinary person scarcely has opportunity to produce a small fraction of what she is capable of.

The potential and opportunities of parents and siblings tends to be limited (sometimes severely) by the presence of PMH Salim, at least in some directions, though arguably extended in others. PMH Zhenya's mother is unlikely to be able to study to be a lawyer or to write travel books *in addition to* caring for Zhenya. But the potential for interior/spiritual/human growth is there: the challenge moves into the home, rather than the person having to go out to seek external Himalayas to conquer. *Recognition* of achievement in likely to be a good deal less, with the result that the significance of achievement may be much diminished for the person concerned. There are no Nobel prizes for heroic struggle and achievement in the PMH household.

Drawing out movement, response, activity, from PMH Ramdas is "good" if one considers and defines it to be good. In some philosophies "it is better to walk than to run, better to stand than to walk, better to sit than to stand, better to lie down than to sit, better to be still than to be in motion." The ILSMH has begun and flourished initially in societies which are dominated by individual activity, consumption of time, use of energy. In such societies it is an offence to be still, inactive, doing nothing purposeful; one should at least be spectating action on film or television. The clash between this activism and other philosophies is inevitable. PMH Ramdas, left to his natural immobility and near-inanition, appears in some views to be complete, whole, fulfilling his destiny. To violate this harmony by modern/Western intervention in the name of some hypothetical "potential", monitoring his brain rhythms, prodding him into response, reinforcing desired behaviour with sweeties doled out, can have the appearance of teaching a dog to stand on its hind legs; or worse, the blunderings of noisy demonstrators across a still garden, heedless of the small flowers trampled underfoot.

There is great difficulty in accepting *differentness*. Provided PMH Suzie lives in

a reasonably warm room there is no reason why she should be pushed and tugged in and out of ordinary clothes. It is done with a view to emphasizing the *likeness* and *normality* of the PMH person, despite the evident artificiality of this. It may more readily be justified in the case of the severely disabled person who can learn enough tricks to "pass" for normal: such a person then has a choice of "passing" or "being different". In some views it is better to have more choices, but the extent to which PMH Salim desires to be given choices remains unclear.

It is demonstrable that Salim can often express a preference of colour, taste, sound etc. if a choice is presented. But that is a different matter from the question whether choice *shoud* be presented. Some people feel strongly that they should; others feel that if billions of dollars are spent on persuading people to choose between brands *X* and *Y* of identical soap powders then the luxury of choice has been seriously abused and corrupted, and a different direction should be taken with the still harmless PMH Maria.

Normalisation, fulfilment of one's potential and the "technological imperative" to use to the full the most complicated and expensive machinery available, have been the progressive trends during ten years, and are even now being exported with proselytising enthusiasm to countries in the early stages of their public rehabilitation services. A counter-movement of accepting differentness; of being proud to be black, gay, female, PMH; of small-is-beautiful, "Buddhist" economics, appropriate technology; of renunciation; of non-participation in games of competition and fulfilment; of other as yet unseen persuasions; is under way. The outcome of these often-conflicting waves remains to be seen.

Different Beliefs, Different Conclusions

The purpose of this chapter was to expose some of the roots of philosophy and religion underlying different approaches to PMH Maria and Okeke, including some which may be distasteful or abhorrent to the participants of the ILSMH. For the purpose of campaigning for a better life for Maria and Okeke and their counterparts in many countries it is necessary to face the realities of their context and of public attitudes that may be encountered. Some negative attitudes are amenable to a reasoned presentation of facts. Others arise from deeply held beliefs which may require a different approach or may even be impervious to argument.

What *should* be done in each community, nation or region may best be prescribed by the leaders and concerned persons in those parts, having taken cognizance of what is done elsewhere. The fact that the majority of nations subscribe to certain declarations, e.g. of Human Rights, gives some evidence of universally recognised moral and ethical principles. But it is precisely at the boundaries of human life and experience, i.e. where PMH Salim and Zhenya find themselves, that the generally held principles are found difficult to apply, and different solutions are attempted in different places. Furthermore it is apparent from studies of individual moral development that the great majority of Western populations and individuals fall short in their personal conduct of the high moral and ethical principles enshrined in the U.N. declarations. There is little evidence to suggest that non-Western populations are any different in this shortcoming.

Further difficulties arise if one attempts to determine priorities when a limited social welfare budget is available for a very wide range of needs, whether the resources comprise money, time, equipment or personnel.

Therefore, while reiterating the League's previous decisions and commitments to all mentally handicapped persons, and recording the resolutions put up by the present Conference, it is not ultimately and universally possible to spell out "What Should Be Done".

Derek Fisher

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Getting It Done

It would be idle to pretend that PMH Ramdas, Maria and Okeke have very much going for them in their different regions of the world. The most one can say is that, for the majority of PMH persons, knowledge, techniques, equipment and strategies have been discovered that could make a considerable difference to their survival, comfort and living skills. Distribution of that knowledge and equipment, those techniques and strategies, is marginal. Financing for them is practically invisible. Public interest and awareness is virtually non-existent.

The latter is a crucial factor. It is not perhaps sufficiently appreciated that *attitudes* and *services* should walk hand in hand, interacting with one another. Successful service innovations, initiated by people with more progressive attitudes, can be a catalyst to the improvement of attitudes generally; whereas outmoded services based on uninformed and negative attitudes reinforce the negatives and retard positive attitudinal change. But service innovations requiring attitudes too far in advance of the public climate may fail for lack of broad community support; the failure then reinforces the very attitudes that should have changed. The art of rehabilitation politics is to keep up a steady forward pressure along a broad front, while siezing the right moment for a major push at particular points.

There can be little doubt that without a good measure of Government financing, the distribution of knowledge, equipment, techniques and strategies will remain confined to a few isolated spots with a handful of beneficiaries. To have any realistic chance of "Getting It Done", families of PMH Salim and Zhenya together with interested professionals in each country need to plan a campaign over a five or ten year period, having clearly defined objectives and a hard-boiled plan for reaching them. "Society", "Government", "Financing", are large, profoundly amorphous blobs which can absorb random impacts without any visible or practical effect. But they can be shifted and reshaped a little by a carefully organised and well-timed input.

Resources Available

The experience gained by the ILSMH and its component members in campaigning for mentally handicapped persons in general constitutes a major international and cross-cultural resource to direct into a campaign for profoundly handicapped persons. It is unnecessary to repeat the mistakes of earlier campaigners, since the obstacles facing PMH Suzie and Okeke now are broadly similar to those faced by all mentally handicapped persons 20 years ago.

Various publications of the ILSMH, its booklets and its conference proceedings, are recommended reading for anyone seriously intending to campaign for PMH Salim and Ramdas. These materials in fact contain an adequate description of the various community resources available, and methods of mobilising them.

In countries where the League has no members, there are likely to be other groups or movements which have achieved reform in various fields by educating the public and persuading the Government. Some of these countries may require very different methods of approach to those which have succeeded in Europe and North America. The point is that the experience, mistakes and successes of others is an important resource that will repay study.

Each member society of the League is likely to constitute the major campaign base in its own country, but this is not inevitably so. There will be a tension in some associations between existing campaign targets and any new proposed target. Members who have given priority to a campaign for the "average" moderately handicapped person may resent any diversion of efforts and scarce resources to the minority of the profoundly handicapped. Proponents of the latter may feel that they need a distinct and separate identity. In associations where the moderately handicapped members are being accorded a greater say in budgetary decisions, advocates for the profoundly handicapped may find themselves in an uneasy position. Care needs to be taken to ensure that not too much of the energy that should be given to converting the Government and general public is dissipated in local association politics and infighting.

Tackling the Government; Tackling "Them"

Encounters between disability campaigners and Government officials are often characterised by mutual incomprehension. The Government side knows very little about disability, and from what it hears the problems appear to be messy, straggly, open-ended and difficult to reduce to any sort of order. Many different departments seem to be involved, and the civil servant knows the difficulty of getting any two Government departments to cooperate. Meanwhile the disability campaigners usually know very little about Government and how it functions. How are decisions taken, and by whom? Where and at what time of year are budget allocations made? At what point, and on which person, should pressure be applied? What can one realistically expect the Government to *do*? Is it the politicians who run the show, or are the civil servants really more important?

Since each Government is different from every other one it is impossible to give a blueprint for tackling Governments. But the onus is definitely on the campaigners to avoid the mutual incomprehension outlined above. Realistically, Government officials cannot be expected to know anything about disability and rehabilitation, least of all the complex condition of PMH Maria. It is the campaigners' task to supply concise, accurate information in a shape and form than can be assimilated By the Government. That in turn entails finding out how Government works; which department has what responsibility; what each department is currently doing; if possible, what it plans to do in the next year or two. In some countries this sort of information can be dug up in public libraries. In most countries it needs to be searched for and acquired by persons with influence, after many visits and much letter writing.

Having acquired some understanding of how Government works and what it is doing, the advocates for PMH Zhenya need to martial their facts and figures, presenting a clearly stated and well argued case for a series of actions to be taken, with the probable benefits resulting. If possible, some alternative routes may be proposed, to reach broadly similar goals. This not only impresses the bureaucrats with the thoroughness of the case, but more importantly it enables them to exercise some choice and thereby play a role, leave their mark, without actually having to know very much about the case. In

some countries it may be advisable to request some highly improbable actions, together with a small number of reasonable actions which are the real target. This enables the bureaucrat very happily to turn down most of the requests, while granting the few reasonable ones as evidence of his generosity and magnanimity, after the customary months of delay.

Very often PMH Salim's family will not be immediately interested in tackling a Government, but will have set themselves a more modest goal such as persuading one particular hospital to install a small ramp and to permit the service lift to be used for Salim's trolley, so that Salim can attend physiotherapy sessions without obliging his brother to carry him along two corridors and up three flights of stairs. Similar principles apply: to get to know how the hospital is administered, who is responsible for what, who takes decisions and who implements them; and then to set out a clearly argued case preferably with benefits accruing more widely than just to Salim, making it difficult for the hospital officials to disagree with it.

It is important to study *motivation*, whether tackling Government, hospital, school, or clinical psychologist. The "reasonable" requests for assistance with PMH Ramdas are likely to cost a tiny fraction of the national health budget, which is itself a small fraction of what most nations spend on "Defence". Requests to an institution for a small timetable change so that Okeke's father can attend therapy sessions and co-ordinate them with home rehabilitation is unlikely to bring the whole institution grinding to a halt. Many requests can perfectly well be met, if the official deciding the matter has sufficient motivation to do so. In the absence of such motivation, the bureaucratic reflex of red tape, precedent, tradition and inertia are likely to block the way. To change this unwanted behaviour it is necessary to study the relevant officials and discover what motivates them, and how much freedom of action they have. Parents of PMH Suzie may *feel like* screaming at the petty bureaucrat, doctor or teacher who is blocking them, but to do so is useless unless there is evidence that this person gives way in the face of screaming parents.

In presenting a case, any of the arguments outlined at the beginning of the previous chapter may be utilised. Relevant case studies may be included, preferably attested by senior consultants. It may be very fruitful to persuade Government officers of suitable rank to visit a model project and see for themselves what can be done for and with PMH Zhenya. "Advocacy" may extend to striking a bargain with the Government whereby a local association sets up a model project and runs it for three years after which, subject to positive evaluation report, the Government may adopt and replicate it more widely.

Attitudes, Communication and the Media

As previously stated, attitudes towards PMH Suzie and Ramdas are of considerable importance at every stage of "getting things done". Although much talked about in general, there has been very little study specifically of attitudes towards persons with profound mental handicap. There is also remarkably little concrete evidence of effective means to change attitudes. It may be true to say that one cannot directly change other people's attitudes: one can merely supply the information, the context and the catalyst by which some people will modify their own attitudes. Attitudes towards baked beans or a particular brand of micro-computer can be moulded around the notion that the customer's taste-buds will be gratified, or his life will become more interesting, if he purchases the product. The benefits accruing from developing a positive attitude towards PMH Maria are a good deal less tangible even than advertisement fantasies.

Here again, motivation is important. The people most likely to modify their attitudes are those who are less than satisfied with their present attitude. They may, for example, be ashamed at their feeling of fear and revulsion towards funny-looking PMH Okeke, and may wish to replace this with a feeling of warmth and acceptance that would match their image of themselves as kindly folk. To effect this change, they need to meet Okeke in circumstances where he is doing something positive and appealing and where they themselves can control the degree of interaction, i.e. get progressively closer to Okeke as his appeal begins to evoke in them the "better" feelings of which they can approve.

The predominantly negative attitudes towards PMH Salim and Maria, more negative than those directed towards less severely disabled persons, must derive partly from the past when very little success could be achieved with their rehabilitation for lack of the knowledge, techniques and equipment now available. The more that modern methods are applied *and communicated*, the easier it should be for well-motivated persons to develop more positive views. Among the most important targets are parents and professionals themselves. The abolition of the "vegetable" mentality was noted in an earlier chapter as having been effected among "the more enlightened" professionals; but there are still plenty who

adhere to leguminous beliefs, and some who are ready to propagate such views on the mass media.

Both the ILSMH and the U.N. (ECOSOC) have produced intelligent booklets giving guidance on using the mass media effectively. The random spraying out of information and opinions is probably quite effective as a means of auto-suggestion and reinforcement of one's own views but there is little evidence that it produces any benefit to PMH Suzie and Salim, or even their less disabled cousins. Communications should rather be target-specific and goal-directed, taking in lessons from business marketing.

There is some evidence that people modify their attitudes one step at a time through several distinct stages. Here again, the business-like approach would dictate that some study be carried out into current attitudes and behaviour among target groups, leading to a stage by stage effort to achieve modification. This may be unpalatably slow for some advocates. If a key figure in the Health establishment is known privately to favour high doses of tranquilisers and an early death as a solution to problem behaviour by PMH Maria, it is unlikely that he will be persuaded in one step to switch to valueing Maria as highly as he values his own pretty graduate niece. A realistic target might be to shift him first to conceding the right to life, based perhaps on the argument that if institutions begin killing their awkward residents it is difficult to know when to stop: when the most awkward have gone, the less awkward are in line for the axe. At the same time, anticipating the next stage of his re-education, he may be presented with evidence that problem behaviour similar to Maria's has been controlled in other places, and it would be sound practice to make a similar effort with Maria.

Financing and Personnel

In practically every country there is more money *obtainable* and *available* for PMH Salim and Zhenya than is being *utilised*. Some of it is in private pockets and would be transferred if the right appeal were heard. Some of it is lying with ten different Government departments, awaiting an application on the correct forms in triplicate. Some of it is in the shape of shop-worn equipment that would be donated if request were made to the right person. Some of it is sitting in the bank accounts of the U.N. organisations, awaiting a proposal from the Government. Some of it comprises research grants and scholarships. Some of it could be obtained by a more thorough investigation of welfare provisions. Some of it is with the service organisations such as Rotary, Red Cross, Girl Guides etc. The resources are lying untapped in a thousand likely and unlikely places.

In every country there are people who are unemployed, or under-employed, or in full time employment but with empty leisure hours, who would give their time and energy voluntarily to get to know PMH Suzie and to work on behalf of PMH Okeke and their families, if someone were to ask them to do so and were to get them started with a brief orientation.

There are people who would be willing to help Okeke's family discover how the Government functions, with a view to re-educating it. There are people who enjoy fund-raising, regardless of what "good cause" receives the takings. There are people who are permanently embattled on behalf of the downtrodden and under-privileged and who would be only to happy to hurl themselves into the fray on behalf of a case so deserving as PMH Salim.

This is not to say that finance and volunteer help is *easy* to come by. But in most countries there is a good deal more juice in the lemon than may at first appear. It depends partly on how much PMH Zhenya's family want to squeeze help from their community. As discussed in an earlier chapter, there are some families who expect no help and seek no help; who would indeed consider it demeaning to advertise their difficulties. The there are families who expect help to be available automatically from the welfare state, and resent the necessity of applying, appealing, cajoling, pleading for what they believe to be their rights. In between are probably the bulk of families, who while not liking the bother and humiliations involved in obtaining help are nevertheless prepared to go to great lengths to obtain it for the sake of Ramdas and others like him.

The hidden costs of the battle are high for individualists. It *is* possible for parents to campaign for and obtain help and service facilities, in addition to the extra work involved in home care for PMH Salim. But over the years those same parents may find themselves worn down, exhausted, their other children at risk of neglect, their marriage gone stale. Usually the fruits of the campaign are enjoyed less by those who fought than by the next generation. Those who come after, far from being grateful, usually take for granted the hard-won benefits and complain that so little has been achieved.

The key to reducing the costs and obtaining more benefits seems to lie in good organisation, spreading the load and setting realistic targets. Volunteer help is notoriously difficult to organise in a disciplined manner. Delegating responsibilities and working through committees is notoriously difficult in many Third World countries where systems are normally hierarchical and nobody trusts anyone who is not his blood relative. The protagonists are in many cases embroiled in their own family problems centring around PMH Okeke and Suzie, trying to come to terms with a difficult present and an uncertain future. In these circumstances it is advisable to make a realistic inventory of resources, strengths and weaknesses and to set modest, achievable short-term goals within the grander long-term objectives.

Planning realistically

South West Region Society for Very Different Children

Plan for Action, first half of 1986

1) Find lawyer who will advices at low cost how to stop Okeke's family's landlord from evicting them because Okeke often cries at night.

2) Propose to Director, Social Services, that one of his physiotherapy technicians hold a PMH family teaching session fortnightly at the main hospital, where family members will learn how to give exercise and massage limbs.

3) Send delegation to Deputy Planning Commissioner, S.W. Region, who is rumoured to have a handicapped brother, to see if he can exert influence to achieve No. (2).

4) Write to ILSMH, Brussels, for booklet on how to make best use of volunteer helpers.

5) Approach College Students Action Group to see if they would help with a river picnic in the spring for a dozen Very Different Children.

6) Contact Headmaster of the top local school and offer small cash prize for best essay by senior pupil on "How we can help disabled children to enjoy a fuller life".

7) Write to All Ruritania Women's Association (S.W. Region Branch) pointing out that Ruritanian mothers of Very Different Children spend half their lives washing sheets and nappies, and would the A.R.W.A. consider sponsoring a fund to give some relief.

8) Organise regular monthly social get-together for parents where they can exchange experiences and encourage one another.

9) Visit local technical college to see if some of the engineering students could design an adaptable lightweight hoist that could be made at low cost from local materials, by which one small adult or sibling could move large floppy PMH Maria between bed, toilet, bath and chair.

Realistic Targets

What is realistic? For the Director, Social Services, S.W. Region, Ruritania (see page 00) it is realistic to ignore the 70% of disabled persons who live in rural areas, the 10% who live in towns but whom he cannot locate, and the 12% who either do not want rehabilitation services or are not willing to make much effort. He believes he can do nothing for PMH Okeke, so he takes steps to avoid Okeke's family. Suppose Okeke's parents get together with the other 20 active families to form the South West Region Society for Very Different Children. They may jave as a long-term goal a change in central Government policy whereby the Di.ector, Social Services, would have at least ten times the present rehabilitation resources, much of it directed towards community working. But for the next six months they may be well advised to achieve something more practical and probable.

The imaginary program below assumes a certain level of urban living and competence. In some countries it might seem a naive level of activities, while in other countries it would be unlikely that a local parents organisation could achieve this much in six months. The point about this program is that the items are practical and concrete, the results tangible, verifiable and beneficial to PMH persons, and there is a reasonable chance that at the end of six months at least half of them will have successfully been achieved. Nobody can expect to win every battle, but with careful planning it is possible to achieve an encouraging measure of success which then forms the basis for the next realistic plan.

Conference Recommendations

ILSMH Conference on Profound Mental Handicap
Madrid, November 8th and 9th, 1984

1. Rights
Persons with profound handicap deserve respect and dignity. The value of a human being is independent of the nature and severity of his or her handicap. So far as possible, therefore persons with profound handicap should be helped to become more independent in decision making concerning their day to day lives and their future development.

2. Prevention
In many cases, profound mental handicap can be prevented. The League should collect information on possibilities for primary prevention. Everything should be done, according to the resources and capacities of particular countries or regions, to take measures which can prevent or reduce the prevalence of profound mental handicap. Furthermore, more developed countries should do everything in their power to assist less developed countries in, for example, reducing the incidence and effects of severe malnutrition.

3. Information, Attitudes and Acceptance
The League should strengthen its efforts to bring together information which would assist governments and other organisations to encourage a more positive attitude to persons with mental handicap among politicians and fellow citizens, in order to ensure that they can take their rightful place in society.

4. The Special Assistance for Particular Life Situations
Mothers and fathers who are confronted by the birth of a child with profound handicap need particular help. Some of the League's members have been able to provide invaluable help for such families – e.g. by Family to Family Support Programmes. The League should disseminate information on this subject and try to convince governments that help of this nature is necessary and worthy of full financial support.

5. Early Help
All specialists are unanimous that early intervention to assist children with profound handicaps as well worth-while. The League should disseminate information on possibilities for progress. The League is asked to call a conference on this specific theme of care and early intervention for children with profound handicaps.

6. Institutional Services
A very wide range of attitudes and opinions was reflected in the discussions on this subject. Different views were expressed on the possible contribution that can by residential institutions. However, it was unanimously agreed that even persons with profound mental handicap can and should be helped to live as normal a life-style as possible. In some countries (in particular Sweden, Denmark, the United Kingdom and North America), the number of people in large institutions is being gradually reduced, and in many cases institutions are planning for total closure. In other countries, however, institutions are just in the process of being established, in order to provide a better quality of life for persons with profound handicap (e.g. Spain and some Asian countries).

The League should therefore do everything possible by means of contacts with its member societies, to disseminate information about the pattern of provision in different countries. Everything should be done to provide information on ways in which the quality of life in existing institutions can be improved, so that residents can live as normal a life-style as possible.

7. Living Arrangements
The development of a wide range of living arrangements for persons with profound handicap should be supported. The League should stimulate the exchange of information concerning the range of possible developments and facilities. For example, information needs to be shared on ways in which foster families can assist parents in providing alternative accommodation into main ordinary housing to relieve parents but also to provide the person with profound handicap with the experience of living in another environment. A range of housing units should be available in which children and adults can be accommodated for a matter of a few weeks.

8. Education
All individual are capable of some degree of learning, no matter what their age or degree of impairment. It is therefore essential to develop appropriate opportunities for learning both in and out of school.

9. Schooling
Children with profound mental handicaps should have full access to whatever eductional facilities are available to other children. For example, schools should widen the range of learning opportunities available to all children, and aim for the maximum degree of integration between handicapped and non-handicapped children which is considered appropriate to local circumstances.

10. Work and Occupation
Some form of meaningful occupation should be available to all persons with mental handicap, irrespective of the nature and severity of their impairments.

11. The Need for Assistance and Services when Parents are no Longer able to Care for their Child
The League should provide examples of good practice on ways in which this difficult question has been approached. Provision which is made for persons with profound mental handicap after their parents are no longer able to care for them has to be acceptable both to the family and to the person concerned.

12. Partnership between Parents and Professionals
Parents and professionals should work together as a team in order to work for the learning and development of the person with handicap. The League, as the representative of parents, should do everything in its power to foster such partnerships.

13. Multi-disciplinary Partnerships between Professionals
Specialists who are concerned with different aspects of disability should undertake at least some degree of joint training. Every professional should know something of the background of knowledge and skills of other relevant professionals.

14. Training of Personnel

Staff working with persons with profound handicap should be trained to the highest possible standard. The family training workshop, organised by ILSMH in Hong Kong, has demonstrated that a great deal of information and skill development can take place in a period as short as one week. Over and above any technical skills possessed by staff, the more qualitative and human skills needed by staff should not be overlooked.

In order to assist the training of staff, information sharing and exchange of personnel between countries should be encouraged. The League's Partnership Market is a first step in the right direction.

Symposium Papers

The full papers presented at the Conference are listed below, and may be obtained from the Secretariat of the ILSMH.

Dr. Heidemarie Adam:
Communicating with persons who are profoundly handicapped.

Ms. Gerd Anden:
19 years together with my profoundly handicapped son. His needs and possibilities.

M. Jean Claude Cousin:
Possibilities for Action of Parents of Profoundly Handicapped Persons.

Dr. Lucille George-Janet:
Training of Staff working with profoundly handicapped persons.

M. Pierre Hautier:
Parents, the couple and the child.

Dr. James Hogg and Ms. Judy Sebba:
Profound Retardation and Multiple Handicap – What do we mean and where are we going?

Sr. Rafael Riestra Limeses:
Thoughts of a Parent of a Handicapped Person.

Ms. Judy Sebba and Dr. James Hogg:
Education in and out of School.

Mr. Dafydd Wigley, M. P.:
The Roles of Government and Community.

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The International League of Societies for Persons With Mental Handicap.
Founded in 1960 by representatives of societies of parents of mentally handicapped persons, friends, and professionals in the field of mental retardation, the ILSMH is devoted to defending the rights and interests of mentally handicapped persons without regard to nationality, race, or religion. The League addresses problems related to mental retardation: among them are prevention, diagnosis and early treatment; education and training; economic security; social welfare and integration; guardianship; interfamilial relations; due process of law and public education.

In order to achieve these objectives, the League, with the help of its member societies, organizes international symposia of experts, regional conferences, and world congresses. The League publishes the results of these efforts, an international newsletter translated in four languages, and various pamphlets on topics of general interest. The League has consultative status with UNESCO, ILO, WHO, ECOSOC, and the Council of Europe, and has official relations with other international organizations interested in handicapped persons.

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